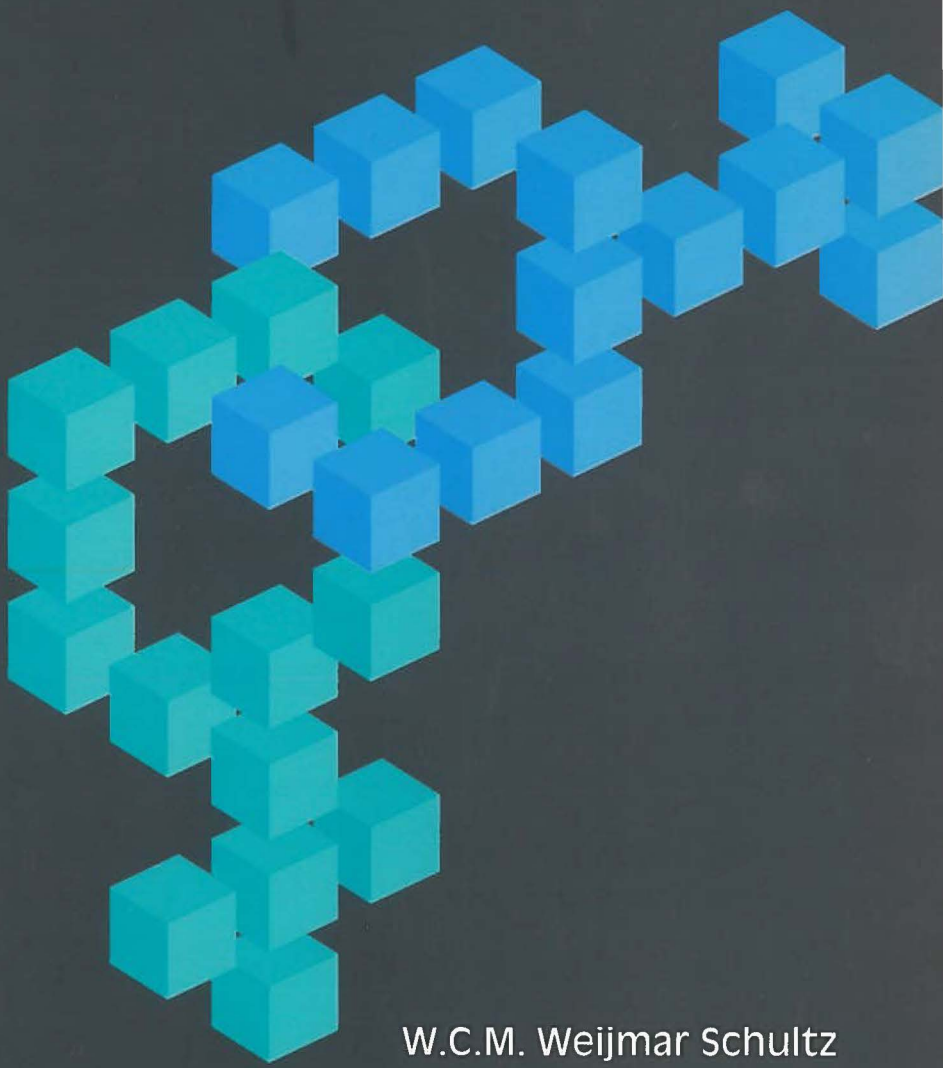
Sexual functioning after gynaecological cancer treatment

Wiel, Henricus Balthazar Maria van de; Weijmar Schultz, Willibrordus Canisius Maria

SEXUAL FUNCTIONING

AFTER GYNAECOLOGICAL CANCER TREATMENT



W.C.M. Weijmar Schultz

H.B.M. van de Wiel

SEXUAL FUNCTIONING AFTER GYNAECOLOGICAL CANCER TREATMENT

Stellingen

behorend bij het proefschrift van Harry B.M. van de Wiel

SEXUAL FUNCTIONING AFTER GYNAECOLOGICAL CANCER TREATMENT

1. Confrontatie met gynaecologische kanker leidt doorgaans tot een toename van ambivalente gevoelens ten aanzien van seksualiteit en slechts zelden tot seksuele emancipatie.
   (dit proefschrift)

2. Hoe groter de crisis voor het individu, des te minder individueel het zich gedraagt.
   (dit proefschrift)

3. Een radicale hysterectomie kan om psychologische redenen de seksuele respons verstoren.
   (dit proefschrift)

4. In psychologisch opzicht krijgt niet alleen het individu kanker maar het hele gezin.

5. Door de hiërarchisch geneste opbouw van gedrag, blijft het steeds de vraag wat men onder "welzijn", i.c. seksuele satisfactie, dient te verstaan.

6. De onenigheid op het punt van de methode betekent eigenlijk dat men het nergens minder over eens is dan over de manier om het eens te worden.
   (De Boer: Tussen filosofie en profetie, 1987)

7. Een probleem op de polikliniek Psychosomatische Gynaecologie is dat mensen zich niet willen laten helpen.

8. Gesponsord seksuologisch onderzoek vormt een link tussen het bedrijven van de liefde en de liefde van het bedrijf.

9. Aan ieder thuis zit een luchtje, behalve bij ons.
   (Floortje, 8 jaar)

10. De natuurwetenschappen hebben laten zien dat reductie tot productie kan leiden; de natuur zelf demonstreert nu dat productie tot reductie kan leiden.

11. Voor wie kan klappen met één hand, is empirisch onderzoek overbodig.

12. Ook van dingen zonder handen kun je een klap krijgen.
    (Anne, 6 jaar)

13. Het verwerven van assertiviteit loopt van waardig, via vaardig naar aardig.

14. Carrière maken is een sterk overschatte vorm van vermijding.

15. De lage status van "opvoeders" heeft niet zozeer te maken met de afwezigheid van de daarvoor benodigde vaardigheden als wel met de onzichtbaarheid daarvan.

16. Bij de bakker doe je "broodschappen".
    (Pim, 4 jaar)

17. Uit het nieuwe Hite-report blijkt dat 34% van de mannen een orgasme simuleren.
    (Van Kooten en De Bie, Bescheurkalender)

18. Het therapeutische rollenspel kan gezien worden als een inhaalactie voor diegenen voor wie het leven nimmer een spel was dat op rolletjes liep.

19. Racewagens ogen sneller naarmate ze langzamer rijden.

20. Worüber man nicht sprechen kann, muss man einen Psychologen zu Rate ziehen.

21. Bij multidisciplinaire samenwerking is het noodzakelijk contact-tics om te zetten in con-tactics.
    (H.B.M. van de Wiel, C.M.J. Boon & W.C.M. Weijmar Schultz, Gedragstherapie, 1991)

22. Dat mensen op hun werk de krant lezen geeft aan dat er iets goed mis is in deze wereld.

23. Minnen heeft plussen.

Stellingen

behorend bij het proefschrift van Willibrord C.M. Weijmar Schultz

SEXUAL FUNCTIONING AFTER GYNAECOLOGICAL CANCER TREATMENT

1. Het is onterecht om bij de voorlichting aan gynaecologische kankerpatiënten seksualiteit buiten beschouwing te laten.
   (dit proefschrift)

2. De motivatie voor seksueel kontakt na de behandeling van gynaecologisch kanker is belangrijker dan welke fysieke belemmering ook.
   (dit proefschrift)

3. Een radicale hysterectomie kan om fysiologische redenen de seksuele respons verstoren.
   (dit proefschrift)

4. De perceptie van genitale symptomen gedurende seksuele opwinding is geen goede graadmeter voor de tevredenheid over het seksueel funktioneren.
   (dit proefschrift)

5. Het herstel van het seksueel functioneren na oncologisch gynaecologische behandeling is meer een kwestie van woorden dan van daden.
   (dit proefschrift)

6. "Als je meer over de vrouw wilt weten moet je je eigen ervaringen nagaan of de dichters raadplegen.....".
   (Freud, 1933)

7. Een probleem op de polikliniek psychosomatische gynaecologie is dat mensen zich zo graag willen laten behandelen.

8. "Any treatment that has the power to help has also the power to hurt".
   (Le Shan, 1990)

9. Een meersporenbeleid, waarbij aandacht wordt besteed aan de interaktie tussen psychoseksuele, relationele en somatische aspekten komt in de gynaecologische praktijk niet zelden als mosterd na de maaltijd.

10. Het grote aantal patiënten met onbegrepen buikklachten is een teken aan de wand.

11. Een geknipt perineum bij een ongecompliceerde eerste bevalling is een verknipt perineum.
(W.C.M. Weijmar Schultz, H.B.M. van de Wiel, R. Heidemann, J.G. Aarnoudse & H.J. Huisjes, 1990, Journal of Psychosomatic Obstetrics and Gynaecology, 11, pp. 119-127)

12. Kortere wachtlijsten voor IVF kan leiden tot het ongewenst vroeg uitvoeren van IVF.

13. Bij iedere operatie hoort een bijsluiter.

14. De uitval van deelnemers aan een gerandomiseerd onderzoek verloopt niet gerandomiseerd.

15. Het best bewaarde geheim van Nederland: Groningen.
(Humphrey, 1986)

16. Promoveren is meer een kwestie van avonduren dan van avonturen.

17. Veranderen is voor anderen.

18. De rijken rest eten, de armen eten resten.

19. Er zijn mensen die zitten in ieder circuit, behalve het huiselijke.

20. Kennis is macht, kennissen is meer macht.

RIJKSUNIVERSITEIT GRONINGEN

SEXUAL FUNCTIONING AFTER GYNAECOLOGICAL CANCER TREATMENT

PROEFSCHRIFT

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op gezag van de Rector Magnificus Dr. L.J. Engels
in het openbaar te verdedigen op
woensdag 27 februari 1991
des namiddags te 3.00 uur precies

door

HENRICUS BALTHAZAR MARIA VAN DE WIEL
geboren op 26 juni 1955
te 's-Hertogenbosch

&

des namiddags te 4.00 uur precies

door

WILLIBRORDUS CANISIUS MARIA WEIJMAR SCHULTZ
geboren op 30 januari 1948
te Rijssen

1991

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Preface

This dissertation is the result of a close cooperation between a gynaecologist and a psychologist. A bi-disciplinary approach requires the combination of two different scientific disciplines, each with its own methodological and ideological background. Although two types of readers were aimed at, physicians and psychologists, we were unable to avoid that the accessibility of some parts of the study may be limited. This goes for physicians as well as psychologists.
Because the dissertation is based upon a number of articles, published over the last few years, there may be some overlap in the text.
At the official part of the PhD ceremony the chapters 2.1-2.4.4 / 3.3-3.3.4 / 5 / 6.3 / 6.5 / 6.6 / 6.8 and 6.9 will be defended primarily by Harry van de Wiel. The chapters 2.5-2.5.7 / 3.1 - 3.2.5.4 / 4 / 6.1 / 6.2 / 6.4 and 6.7 will be defended primarily by Willibrord Weijmar Schultz. This division is not valid for the chapters 1, 6.10 and 7.

We suffered years from this book, now it's your turn.

A WORD OF THANKS: THANKS!

A special word of thanks goes to prof. dr. P.E. Boeke, to whom we would like to refer as one of the promotors of this book.

CONTENTS

* Weijmar Schultz, W.C.M., Wiel, H.B.M. van de, Bouma, J. & Lappöhn, R.E. (1991) Gynaecological conditions and sexual dysfunction. Accepted by Sexual and Marital Therapy.

* Weijmar Schultz, W.C.M., Bransfield, D.D., Wiel, H.B.M. van de & Bourna, J. Sexual outcome following female genital cancer treatment; a critical review of methods of investigation and results. Accepted by Sexual and Marital Therapy.

* An abstract from "A system theory approach to the sexual consequences of genital cancer". Wiel, H.B.M. van de, Weijmar Schultz, W.C.M. & Thurkow, F.G. (1990). Accepted by Sexual and Marital Therapy.

Samenvatting

Kanker wordt vaak gezien als een breekpunt in het leven van mensen omdat het een aanzienlijke wijziging teweegbrengt in de wijze waarop mensen zichzelf en hun toekomst zien. Bovendien kan de behandeling van het kankerproces tot onherstelbare fysieke beschadigingen leiden met als mogelijk gevolg de aantasting van lichaamsfunkties zoals, in geval van gynaecologische kanker, het verlies van vruchtbaarheid, een vervroegde overgang, het verlies van de menstruatie en aantasting van seksuele funkties.

Het bijzondere van gynaecologische kanker is, dat net als bij borstkanker niet alleen de fysieke integriteit van de vrouw ernstig wordt verstoord doch tevens dat gedeelte van haar lichaam dat in wel heel bijzondere zin bijdraagt aan de beleving van het vrouw-zijn. Dit betekent, dat niet alleen haar lichaamsbeleving in algemene zin ontregeld raakt, doch dat ook haar identiteit als vrouw rechtstreeks wordt aangetast. Het seksueel funktioneren kan daarin een belangrijke funktie hebben.

Wij stelden in ons onderzoek de volgende twee vragen centraal (hoofdstuk 1):
1. Hoe verloopt het seksueel funktioneren in de tijd, te beginnen vanaf het moment van de confrontatie met gynaecologische kanker tot aan een moment waarop geen veranderingen meer te verwachten zijn? Welke rol speelt de factor tijd in dit proces van aanpassing?
2. Hoe induceren en controleren intrinsieke en extrinsieke factoren seksueel gedrag voor en na gynaecologische kanker? Welke psychologische en fysiologische mechanismen reguleren het proces van het seksueel funktioneren na gynaecologische kanker?

In hoofdstuk 2 wordt een algemeen theoretisch seksuologisch kader geformuleerd om tot een beschrijving te kunnen komen van de invloed van gynaecologisch oncologisch handelen op de seksualiteitsbeleving. Er wordt daarbij aandacht besteed aan zowel sociale, psychologische als somatische aspecten.

In hoofdstuk 3 wordt, in zoveel als mogelijk ook voor niet-gynaecologen begrijpelijke bewoordingen, een overzicht gegeven van frequentie van voorkomen, oorzakelijke momenten, symptomen, de wijze van verspreiding en de behandeling van de meest voorkomende vormen van gynaecologische kanker. Er wordt duidelijk gemaakt dat de behandeling van gynaecologische kanker verre van ideaal is. Niet alleen het zieke orgaan en de direct omgevende weefsels worden verwijderd of vernietigd, maar ook omgevende gezonde organen worden vaak beschadigd en de anatomie van het kleine bekken wordt veranderd. De consequenties die dit kan hebben voor de mechanismen die ten grondslag liggen aan de seksuele respons komen gedetailleerd ter sprake.

Vervolgens worden, in zoveel als mogelijk ook voor niet-psychologen begrijpelijke bewoordingen, de consequenties besproken die gynaecologische kanker en de behandeling ervan kunnen hebben voor het psychologisch funktioneren. Psycho-

logische funkties die als gevolgen van gynaecologische kanker en de behandeling ervan bedreigd worden zijn 1) het gevoel van eigenwaarde en het gevoel 'vrouw' te zijn, de gender-identiteit, 2) het gevoel controle te hebben over de seksuele respons en andere lichaamsfunkties, zoals onder andere het vermogen tot voortplanting, en 3) de beleving van intimiteit. Bovendien doet het gegeven kanker te hebben afbreuk aan levenskracht en levensvreugde, en diezelfde wetenschap induceert angst, verdriet, depressie, verwardheid, vermoeidheid en andere stemmingsbelemmeringen met eveneens directe gevolgen voor het algemeen en seksueel funktioneren.

Aan de hand van een geïntegreerd model wordt duidelijk gemaakt dat, op psychologisch niveau, niet alle veranderingen in het seksueel funktioneren na behandeling voor gynaecologische kanker automatisch seksuele problemen of dysfunkties tot gevolg behoeven te hebben. Of onvrede over het seksueel funktioneren ontstaat hangt mede af van persoonlijke factoren, sociale factoren en de context waarin deze (negatieve) veranderingen zich afspelen.

In hoofdstuk 4 worden methoden van onderzoek en resultaten van bestaande studies bestudeerd en van een kritisch commentaar voorzien. Het valt op dat vóór 1980 bijna alle gepubliceerde studies over het seksueel funktioneren na gynaecologisch-oncologisch handelen retrospectief van opzet zijn. Pas na 1980 verschijnen er met een zekere regelmaat artikelen over onderzoek dat prospectief is opgezet. De retrospectieve onderzoekingen, waarvan de resultaten om tal van in dit hoofdstuk beschreven redenen louter "indicatief" genoemd mogen worden, schetsen een erg somber beeld van het seksueel funktioneren na gynaecologisch oncologisch handelen. De prospectieve onderzoekingen laten een veel genuanceerder en tegelijkertijd minder dramatisch beeld zien. Het seksueel funktioneren is weliswaar ernstig verstoord, doch louter in de symptomatische periode voorafgaande aan diagnose en behandeling en in de periode direct volgend op de behandeling. Ook verschillen tussen de gevolgen van de diverse behandelingsvormen zijn minder groot dan op basis van retrospectief onderzoek werd aangenomen.

Waarom het seksueel funktioneren van sommige vrouwen wel en andere vrouwen niet problematisch wordt na behandeling voor gynaecologische kanker wordt uit de bestaande literatuur niet duidelijk.

Hoofdstuk 5 gaat over de methode van onderzoek. Oorspronkelijk werd gekozen voor een multivariate modelsgewijze evaluatie van de gegevens uit het onderzoek. Daarvoor is een groot aantal deelnemers aan het onderzoek gewenst. Dat bleek in de praktijk niet haalbaar. Om deze reden moest de modelsgewijze evaluatie van gegevens verlaten worden en kreeg het onderzoek een ander karakter, namelijk prospectief longitudinaal, vergelijkend en correlationeel.

De informatie werd vergaard door middel van vragenlijsten, door middel van interviews en speciaal ten behoeve van dit onderzoek ontwikkelde meetinstrumenten.

In hoofdstuk 6 wordt, artikelgewijs, het resultaat van ons onderzoek naar de seksualiteitsbeleving na oncologisch gynaecologische behandeling gepresenteerd. *Artikel 6.1* betreft de pilot-studie. Deze was retrospectief van opzet en werd uit-

gevoerd bij tien vrouwen gemiddeld twee jaar na radicale vulvectomie wegens vulvacarcinoom. Ook hun partners werden bij dit onderzoek betrokken. Het resultaat is opmerkelijk. Ondanks vele problemen meldden vier van de tien echtparen een geheel, en eenzelfde aantal een gedeeltelijk herstel van hun seksuele relatie tot tevredenheid van alle betrokkenen. Een zo gunstig resultaat werd niet verwacht omdat de op dat moment beschikbare, voornamelijk Amerikaanse literatuur een vrij somber beeld schetste van de seksuele rehabilitatie na radicale vulvectomie: "as many as 50-90% of the women may stop all sexual activity" (Andersen 1986).

Wat in de gesprekken met de patiënten en hun partners vooral opviel was dat de motivatie om tot seksuele interaktie over te gaan belangrijker was dan welke fysieke belemmering ook. Dit belang van de motivatie was tot dan toe in de literatuur nog niet als zodanig onderkend. Diezelfde motivatie, of beter gezegd de afwezigheid ervan bij zowel patiënte zelf als partner, zou het achterblijven in herstel van de seksuele relatie kunnen verklaren in de leeftijdscategorie van vrouwen boven de zestig. Er wordt kennelijk berust in de veranderde situatie.

Artikel 6.2 gaat over de ontwikkeling van een methode voor het meten van de gevoeligheid van de vrouwelijke geslachtsorganen. Behandeling van gynaecologische kanker door middel van operatie, bestraling of chemotherapie kan zenuwweefsel beschadigen of vernietigen. Dat kan leiden tot een afname, of, indien prikkelremmende structuren in het zenuwsysteem worden aangetast, een toename van genitale sensaties. Treedt dergelijke schade op, dan kan dat interferen met de waarneming van de seksuele respons. Hierdoor verandert het subjectieve gevoel van opwinding wat, op zijn beurt, de genitale respons weer kan veranderen. Aangezien een gestandaardiseerde, objektieve methode voor het meten van de genitale gevoeligheid ontbrak terwijl dit toch een belangrijk onderdeel van het onderzoek vormde, werd besloten een dergelijke meetmethode te ontwikkelen.

Er werd gekozen voor een controleerbaar signaal in de vorm van een electrische prikkel. Bepaling van de gevoeligheidsdrempel per lokatie (= de laagste intensiteit van een elektrische prikkel, uitgedrukt in mA, die bij een bepaalde frequentie en duur van de prikkel een gevoels-sensatie geeft) geeft een maat voor de innervatiedichtheid en dus voor de gevoeligheid ter plekke. Op deze wijze gelukte het bij zestig gezonde vrouwen, onder niet erotische omstandigheden, de gevoeligheid te bepalen van de handrug, de buikwand en de geslachtsorganen.

De geslachtsorganen bleken onder deze omstandigheden minder gevoelig dan handrug of buikwand. De vaginawand, gemeten op 2 tot 4 cm voorbij de introïtus, was nog het minst gevoelig voor de elektrische prikkels. Op dit niveau van de vaginawand bleek de "12-uurs positie" (de voorwand van de vagina) in vergelijking met de rest van de vaginawand weer relatief gevoelig. Deze relatieve gevoeligheid van de voorwand van de vagina stemt overeen met anatomische bevindingen. Deze bevinding ondersteunt eveneens het concept van de clitoro/vaginale sensorische arm van de orgastische reflex met name ten aanzien van de bijdrage van de voorwand van de vagina (de zogenaamde "G-plek") en de zenuwvoorziening direct daaraan gekoppeld.

In *artikel 6.3* wordt verslag gedaan van de ontwikkeling van vragenlijsten om de seksuele opwindbaarheid, de zogenaamde "sexual arousability", te kunnen meten en

het belang dat iemand hecht aan en de atraktiviteit van verschillende lichaamsdelen, samengevat onder de noemer lichaamsbeleving of "body-image". Van zowel de seksuele opwindbaarheid als de lichaamsbeleving is bekend dat deze, als gevolg van ziekte of behandeling, ernstig verstoord kunnen raken met consequenties voor het seksueel funktioneren.

In eigen land bleken geschikte vragenlijsten om de seksuele opwindbaarheid en de lichaamsbeleving op betrouwbare wijze te meten niet voorhanden. Internationaal wel, doch deze vragenlijsten waren zonder aanpassing niet geschikt voor de specifiek Nederlandse situatie. Vandaar het besluit twee nieuwe vragenlijsten te construeren, de Groningen Arousability Scale (GAS) en de Groningen Body-Image Scale (GBIS).

De gegevens van bijna 200 bepalingen bij 59 gynaecologische patiënten en 60 gynaecologisch gezonde vrouwen werden geanalyseerd volgens drie psychometrische methoden: item analyse per subschaal via de klassieke testmethode; item analyse per subschaal en per totale schaal via het "Mokken" model voor gerangschikte antwoord categorieën; en item respons analyse per subschaal en per totale schaal via het "Rasch" model voor twee antwoord categorieën.

De resultaten lieten zien dat de schalen voldoende betrouwbaar waren (in sommige gevallen na het weglaten van één of twee items), met uitzondering van de subschaal betreffende negatieve sensaties gedurende de coïtus. Deze vertoonde onvoldoende structuur om als instrument te dienen voor de meting van een onderliggend latent concept.

Gebaseerd op de totale item-pool kon later een korte (14-items), hoog betrouwbare (alfa=.90) nieuwe schaal worden gedestilleerd, de Groningen Arousability Scale-Female (GAS-F), die bovendien zeer fraai het unidimensionale en cumulatieve karakter van de seksuele respons reflekteert. Deze schaal werd echter pas aan het eind van het onderzoek ontwikkeld en kon derhalve niet in deze versie worden opgenomen.

In *artikel 6.4* wordt verslag gedaan van een longitudinaal onderzoek naar de seksualiteitsbeleving van tien vrouwen die een radicale vulvectomie ondergingen. De eerste meting vond plaats bij opname, nog voor het begin van de operatieve behandeling, de tweede meting 6 maanden na de behandeling en de derde en vierde meting 12 en 24 maanden na de behandeling.

Gevonden werd dat alle vrouwen die vóór hun ziekte en behandeling seksueel aktief waren, 1 jaar na de behandeling wat hun seksuele aktiviteiten betreft weer net zo aktief waren als tevoren. Zes maanden na de behandeling werd een toename in onvrede met de seksuele relatie met de partner gemeten. Gedurende de overige observatietijd was de tevredenheid over de seksuele interaktie met de partner niet anders dan voor de operatie en zelfs groter dan de tevredenheid in de controlegroep, ondanks de fysieke schade en een persisterend gestoorde genitale perceptie bij seksuele opwinding. Tevredenheid met de seksuele interaktie met de partner lijkt daarom meer een uiting van tevredenheid over het intimiteitsaspect van de seksuele relatie dan over het opwindingsaspect. Psychosociale factoren vervullen kennelijk een belangrijker rol in het proces van seksuele rehabilitatie na radicale vulvectomie dan lichamelijke beperkingen.

Artikel 6.5 betreft dezelfde populatie patiënten na radicale vulvectomie als in het vorige artikel. De metingen één jaar na de behandeling werden hierin vergeleken met de resultaten van een diepte-interview op dat moment. Deze interviews bevestigden de resultaten van de metingen: een aantal vrouwen blijkt in staat, ondanks de ramp die hen overkomt en ondanks vele problemen, op een effectieve manier met de nieuwe situatie om te gaan. Aan de hand van uitspraken wordt geïllustreerd hoe de betekenis van seksualiteit en de wens om seksueel aktief te zijn voornamelijk worden bepaald door het gevoel de partner op seksueel gebied tegemoet te moeten komen om de harmonie binnen de relatie te bevorderen. Seksueel gedrag lijkt dus vooral in het teken van verbondenheid en/of huwelijkse plicht te staan, conform het "liefdes-ethos" voor vrouwen. In dit kader wordt ook verwezen naar de Equity Theory. Deze theorie omschrijft menselijke relaties als "fair exchange" relaties: raakt de balans verstoord dan leidt dit tot onlustgevoelens en de drang die balans te herstellen. Interventies met als doel seksuele problemen na ingrijpende gynaecologische behandelingen te voorkomen of te reduceren kunnen daarom het best zowel op patiënte als op haar partner worden gericht.
Artikel 6.6 handelt over de rol van de partner en is gebaseerd op interviews met de partners één jaar nadat hun vrouw een gynaecologisch oncologische behandeling onderging. Het betrof hier voornamelijk mannen van vrouwen die behandeld zijn voor baarmoederhalskanker.

Duidelijk wordt dat er bij de mannen sprake is van veel stress: als symptomen hiervan worden behalve lichamelijke spanningsklachten vooral gejaagdheid, onrust en slapeloosheid genoemd. Ook is er aanzienlijke twijfel over het eigen funktioneren. Toch werd er niet om hulp gevraagd, noch in informatieve, noch in emotionele zin.

De relatie werd niet anders beoordeeld dan bij de rest van de Nederlandse bevolking, dat wil zeggen, 80% van de partners beoordeelt hun relatie neutraal tot positief. Minder dan de helft van de mannen meldde desgevraagd dat hun relatie door de confrontatie met de ziekte hechter was geworden.

Op seksueel gebied gaf 38% te kennen problemen te hebben. Net als over de ervaren stress, werd ook hierover niet of nauwelijks gesproken of werden andere aktieve copingstrategieën gebruikt. Het zelf aktief zoeken naar oplossingen, bijvoorbeeld door het bespreekbaar maken van de problemen of alternatieve vormen van seksueel gedrag uit te proberen, gebeurde nauwelijks. De partners gaven aan hun hoop op de tijd te hebben gevestigd, maar dat viel hen wel zwaar.

Als mogelijke verklaring voor het gedrag van de partners wordt aangevoerd dat het hier "mannen onder stress" betreft die zich vast lijken te klampen aan "mannelijke" waarden en normen. Het voordeel van deze vorm van sekserol-rigiditeit is dat gevoelens van zekerheid en controle over de situatie worden bevorderd. De crisis wordt daarmee hanteerbaar. Een belangrijk nadeel is echter, dat hiermee ook de communicatie met de ander vermindert: mannen sluiten zich af, trekken zich terug in zichzelf. Een dergelijke reaktie in een uiterst turbulente en emotioneel verwarde periode kan heel funktioneel zijn. De partner fungeert dan als "rots in de branding". De vraag is echter of dit ook geldt voor de lange termijn. Aangezien een goede onderlinge communicatie een voorwaarde is voor het gezamelijk kunnen oplossen

van problemen, is het mogelijk dat "gesloten" partners een deel van het probleem gaan uitmaken. De stille rots in de branding wordt tot een kille steen des aanstoots. Het onderzoek laat zien dat dit risico niet denkbeeldig is en dat de sociale omgeving, in dit geval de partners, ook een negatieve bijdrage kan leveren aan het herstelproces, een gevaar dat ook dreigt voor hulpverleners.
In *artikel 6.7* wordt verslag gedaan van een vergelijkend, longitudinaal onderzoek naar het seksueel funktioneren van vrouwen met baarmoederhalskanker. Het seksueel funktioneren van vrouwen met baarmoederhalskanker vóór behandeling en het erop volgende jaar werd gedurende eenzelfde tijdspanne vergeleken met het seksueel funktioneren van een op leeftijd gematchte controlegroep vrouwen die om niet-oncologische redenen een abdominale uterusextirpatie zonder adnexectomie onderging. Het seksueel funktioneren van zowel de oncologische als niet-oncologische patiënten werd weer vergeleken met het seksueel funktioneren van een op leeftijd gematchte controle groep gynaecologisch gezonde vrouwen. Om het lange termijn effect van diagnose en behandeling te evalueren werd het seksueel funktioneren van vrouwen met baarmoederhalskanker twee jaar na de behandeling nog eens extra gemeten.

Uit de resultaten blijkt dat, ondanks vele veranderingen en problemen, vrouwen na behandeling voor baarmoederhalskanker er naar streven en er ten dele ook in slagen om naar tevredenheid seksueel aktief te blijven ondanks een persisterend gestoorde seksuele respons en hinderlijke fysieke klachten. Hun seksueel funktioneren lijkt sterk op het seksueel funktioneren van vrouwen na een abdominale uterusextirpatie om niet-oncologische redenen. Resultaten bevestigen recente waarnemingen van anderen op dit gebied. Er werd geen verschil aangetroffen tussen het seksueel funktioneren van de onderzoekspopulatie en een toegevoegde controlegroep van vrouwen met baarmoederhalskanker wier seksueel funktioneren één jaar na de behandeling slechts eenmalig was gemeten. Daarom is het niet waarschijnlijk dat deelname aan het onderzoeksproject in belangrijke mate heeft bijgedragen aan de seksuele rehabilitatie.

Het identieke funktioneren van vrouwen na oncologische en niet-oncologische gynaecologische behandeling wijst op het beperkte belang van de kanker-diagnose en de fysieke variabelen. Het meest belangrijk lijkt toch de confrontatie te zijn met een ingrijpende gebeurtenis, ongeacht welke, en de wijze waarop men daar mee omgaat.
Artikel 6.8 geeft de resultaten weer van een meting van het seksueel funktioneren bij elf vrouwen zes maanden na behandeling voor baarmoederhalskanker in vergelijking met het seksueel funktioneren van een op leeftijd gematchte groep gynaecologisch gezonde vrouwen met daarbij in het bijzonder aandacht voor de tevredenheid over het seksueel funktioneren.

Ook reeds zes maanden na de behandeling voor baarmoederhalskanker bleek dat alle respondenten weer regelmatig seksueel contact hadden met hun partner. Voorts bleek dat de patiëntengroep aanzienlijk van de controlegroep verschilde daar waar het de algemene seksuele ontevredenheid betrof: de patiëntengroep was duidelijk ontevredener dan de controlegroep. Dit verschil in algemene seksuele ontevredenheid ging opmerkelijk genoeg niet gepaard met een verschil in seksuele ontevreden-

heid in relationeel opzicht of met een verschil in waardering van de partner als seksuele partner. De zelfperceptie als seksuele partner daarentegen liet zien dat vrouwen in de patiëntengroep een significant meer negatief beeld van zichzelf hadden als seksuele partner dan de vrouwen in de controlepopulatie.

Deze gegevens wijzen erop dat vrouwen die recent behandeld zijn vanwege baarmoederhalskanker, eerder geneigd zijn zich aan te passen aan hun partners dan andersom, waarschijnlijk als gevolg van een lage zelfwaardering en de verhoogde afhankelijkheid van de partner. Dit aanpassingsmechanisme kan worden gezien als een vorm van cognitieve dissonantiereductie: het "geen zin in seksuele interaktie" is in strijd met het reeds eerder genoemde vrouwelijke liefdesethos. Net als bij hun partners lijkt er ook bij vrouwen na behandeling voor baarmoederhalskanker sprake te zijn van een terugvallen op, ditmaal "vrouwelijke", stereotype gedragspatronen.

In *artikel 6.9* worden prognostische variabelen voor het herstel van de seksualiteit na behandeling van gynaecologische kanker getoetst op hun relevantie. De toets betrof zowel patiënten behandeld vanwege vulvacarcinoom als patiënten behandeld vanwege cervixcarcinoom. Uit de resultaten wordt duidelijk dat het seksueel aktiviteitennivo vóór de ziekte en behandeling en de leeftijd ten tijde van de behandeling een prognostische betekenis hebben. Hoe aktiever op seksueel gebied, hoe geringer gevoelens van onvrede aanwezig zijn na ziekte en behandeling. Tevens bleek dat de jongere vrouwen na ziekte en behandeling relatief meer belang hechtten aan intimiteit dan de oudere vrouwen. De oudere vrouwen lijken het vrijen vooral in het licht van seksuele opwinding (van hun partner) te zien. Ook de zin om te vrijen vertoont na behandeling een relatie met de mate waarin men voor de ziekte en de behandeling seksueel aktief was. Het gevoel van eigenwaarde als seksuele partner en de waardering van de partner in het algemeen hebben een geringe prognostische betekenis. Fysieke variabelen en psychoseksuele variabelen zoals het gevoel van eigenwaarde in sociale situaties en de duur van de relatie hebben in ons onderzoek geen enkele prognostische waarde.

Dit resultaat stemt overeen met de eerder gedane waarneming dat het seksueel funktioneren na behandeling voor baarmoederhalskanker niet of nauwelijks verschilt van het seksueel funktioneren van vrouwen die een abdominale uterusextirpatie hebben ondergaan om niet-oncologische redenen (zie onder 6.7).

De in ons onderzoek prognostisch belangrijke variabelen hebben namelijk niets te maken met de indicatie tot medische interventie.

Terwijl het seksuele gedrag redelijk goed te voorspellen valt, geldt dit niet voor de seksuele respons. Kennelijk spelen voor wat betreft de seksuele respons, in dit onderzoek toegespitst op de genitaalregio, variabelen die meer direct met de behandeling te maken hebben zoals de veranderde gevoeligheidsdrempel ter plaatse van de vaginawand en de korter geworden vagina (zie artikel 6.7). De in dit onderzoek gevonden prognostische variabelen van belang, seksuele aktiviteiten voor behandeling en leeftijd, bieden helaas weinig perspectief met het oog op eventuele hulpverlening, daar zij zich aan beïnvloeding onttrekken. Hulpverlening kan, indien gewenst, wel worden geboden om de onderlinge communicatie (zie 6.6 en 6.8) te verbeteren, met name als het om seksuele problemen gaat.

In hoofdstuk 6.10 worden interne en externe validiteit van het onderzoek besproken en worden de belangrijkste conclusies van het onderzoek nog eens samengevat.

In hoofdstuk 7 worden aanbevelingen voor vervolgonderzoek gedaan. Tevens worden enkele praktische richtlijnen voor hulpverlening gegeven. Hierbij wordt de nadruk gelegd op het verbeteren van de communicatie tussen patiënte en partner én tussen hulpverlener en patiënte.

PART I

SURVEY OF OPINIONS, THEORIES AND RESULTS OF PREVIOUS STUDIES

Chapter 1

Introduction and aim of the study

1.1 Psychosocial Oncology

The study of sexual functioning after treatment for gynaecological cancer can be classified as belonging to the domain of studies on psychological and social aspects of cancer. Although relatively young and still small compared to other areas in cancer research, during the last two decades this domain of psycho-social oncology has been rejoicing in ever increasing interest. Holland[1] mentions the following contributions that have led to this increased concern about the psychological and social aspects of cancer:

1) the new optimism about cure and long survival;
2) new recognition of the needs of cancer patients for multidisciplinary skills, and the value of support gained from fellow patients and families;
3) willingness of physicians to accept a multidisciplinary team approach;
4) new concerns in society about patient's rights to self-determination with regard to knowledge of diagnosis, treatment options, and participation in clininal investigation;
5) recognition of immediate and delayed adverse treatment sequelae associated with curative therapy, with the obligation to assess risk-benefit ratios;
6) need to consider quality of life of patients especially with palliative care;
7) need to design new treatment protocols which include the monitoring of quality of life.

   To this list a relatively new factor can be added:
8) the hypothesized relationship between psychological distress and tumour growth or remission.[2-4]

This development towards increasing interest in psychological and social cancer research, can also be found in the official cancer control policy of the Dutch government: "In the economically highly developed countries we seem to have reached a turning point in what has been, generally speaking, the successful story of therapeutic health care. Not only do the results of the health care industry seem to have come to a standstill, but the reverse of the medal is becoming increasingly apparent. The criteria for success which were valid in the past, are no longer regarded as adequate: less and less value is attributed to simply extending the length of life and greater emphasis is being placed on the quality of life...".[5]

To attain an acceptable level of well-being the cancer patient has to be able to accomplish a number of tasks. According to Moos[6] these tasks can be grouped into seven main categories:

1) dealing with pain, incapacitation and other symptoms;
2) dealing with the hospital environment and special treatment procedures;
3) developing and maintaining adequate relationships with health care staff;
4) preserving a reasonable emotional balance;
5) preserving a satisfactory self-image and maintaining a sense of competence and mastery;
6) sustaining relationships with family and friends;
7) preparing for an uncertain future, in the field of oncology also known as "The Damocles syndrome".

Survivors of cancer have to try to adapt to the situation surrounding the illness and the effects of treatment and to mitigate their distress. Until now, little is known about the psychological effects of recovery. Most patients seem to be able to live a worthwhile life but as Weisman[7] remarks: "Clubs of cured cancer patients would not exist if there was no need for information and mutual support".

Not only the patient has problems with "having had cancer". Partners, parents, children, friends and many others belonging to the social network of cancer patients, also seem to have problems with the practical implications of cancer and especially with the mystical aspects of this life-threatening disease, while at the same time they play an important role in the adjustment of the patient.[8] On the one hand, the social support from so-called "significant others" is known to buffer people against the adverse psychological effects of severe stressors such as cancer and to promote physical recovery.[9-12] On the other hand, if support is not forthcoming, or even worse, if patients get stigmatized and/or discriminated against by significant others, further aggrevation of an already problematic situation takes place.[9,12]

Of all significant others, the partner takes first place because he or she is usually seen as the most important source of emotional support[13] or as Dyk and Sutherland[14] observed: "The spouse is often the key to the patient's success or failure in adapting... to the disability". Problems with the partner are therefore of great concern during the rehabilitation process of the patient and therefore need our attention. This is especially true if an important and specific part of the partner relationship, the sexual relationship, is threatened by the disease or its treatment.

1.2 Sexual functioning after gynaecological cancer treatment; relevance and research questions

1.2.1 Relevance

"In a society that has moved rapidly towards an expanded awareness of sexuality at all ages, these patients will demand, not without justification, that medical science passes both appreciation and expertise concerning this dimension of their disease. They will require and expect therapeutic interventions which will assist them in becoming psycho-sexually as well as physically rehabilitated".[15] Although the earliest concern for sexual problems of cancer patients was already expressed in 1952 by Bard and Sutherland,[16] this does not mean that information about changes in sexual functioning after invasive cancer treatment is being provided routinely. Vincent et

al.[17] found that 75% of the gynaecologal oncology patients reported that they had received no information, regarding sexual adjustment before, during or after treatment. However, whereas 80% of these women desired this kind of information, they also stated that they would not bring up the subject themselves, but preferred the discussion to be initiated by the medical team. A needs assessment by Bullard et al.[18] among (non-specific) cancer patients, revealed that 63% of the participants would have liked to have received more information about sexual functioning after treatment and that 64% would participate in a specific counseling programme on this topic if this should become possible.

A recent study conducted by our group on 1700 ostomates, showed that only 23% had received any information about the possible consequences of treatment on their sexual functioning and that, of this informed group, only 55% had regarded this information as adequate.[19]

To rectify this omission in cancer care, it was decided in 1983, to perform a study on sexual functioning after gynaecological cancer treatment on a group of patients at high risk for developing severe sexual problems.[20]

1.2.2 Research questions

Even in a rather limited field such as sexual functioning after gynaecological cancer treatment, a large number of different questions arise. For this study the following two main questions were selected:

1. What is the course of sexual functioning against time, starting from before the onset of the disease until a specific moment in time after treatment, i.e. when no more changes induced by the disease or treatment are to be expected? What role does time play in the process of sexual adaptation after gynaecological cancer treatment?
2. How do internal and external causal factors elicit and control sexual behaviour before and after treatment for gynaecological cancer? What underlying psychological and/or physiological mechanisms regulate the process of sexual functioning after gynaecological cancer treatment?

To answer these rather broad and general questions, a number of steps were developed which either led to direct answers, if available in the literature, or to clues indicating the direction our own study should take. These steps, which form the chapters of this thesis, also include some basic and rather general information about sexuality, gynaecological cancer, and psychological adaptation after traumatic events, because this study involves two groups of professionals with rather different backgrounds: psychologists and gynaecologists. These steps were:

- A conceptualisation of sexual functioning; social, psychological and somatic aspects (Ch. 2)
- A description of physical and psychological implications of cancer of the female genital tract (Ch. 3)
- A review of methods and results of previous studies (Ch. 4)

- An overview of the used methods and materials of the empirical part of this study (Ch. 5)
- The results of 9 empirical (sub)studies (Ch. 6)
- Future directions and some guidelines to help patients and partners cope with sexual problems after treatment of gynaecological cancer are given, based on the results of the second part of the study (Ch. 7).

REFERENCES

1. HOLLAND, J.C. (1984) New clinical issues in cancer care: research implications. In: J.C. Holland, M.J., Massie & L.M. Lesko (Eds.) Current concepts in psycho-oncology. New York: Memorial Sloan- Kettering Cancer Center, pp. 1-5.
2. SKLAR, L. and ANISMAN, H. (1979) Stress and coping factors influence tumor growth, Science, 205, pp. 513-515.
3. LEVY, S., HERBERMAN, R., LIPPMAN, M. & D'ANGELO, T. (1987) Correlation of stress factors with sustained depresion of natural killer cell activity and predicted prognosis in patients with breast cancer. Journal of Clinical Oncology, 5, pp. 348-353.
4. SPIEGEL, D., BLOOM, J.R., KRAEMER, H.C. & GOTTHEIL, E. (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. The Lancet, pp. 888-891.
5. GEUNS, H.A. VAN (1984) Aspects of official cancer control policy. In: Proceedings from the 5th workshop EORTC Study Group on Quality of life. Denmark, pp. 74-84.
6. MOOS, R.H. & SCHAEFER, J.A. (1984) The crisis of physical illness: an overview and conceptual approach. In: R.H. Moos (Ed.) Coping with physical illness: new perspectives. New York: Plenum Publishing Corporation, pp. 3-25.
7. WEISMAN, A.D. (1984) A model for psychosocial phasing in cancer. In: R.H. Moos (Ed.) Coping with physical illness: new perspectives. New York, Plenum Publishing Corporation, pp. 107-122.
8. LICHTMAN, R.R. & TAYLOR, S.E. (1986) Close relationships and the female cancer patient. In: B.L. Andersen (Ed.) Women with cancer. New York, Springer-Verlag, pp. 233-256.
9. BLOOM, J.R. (1986) Social support and adjustment to breast cancer. In: B.L. Andersen (Ed.) Women with cancer. New York, Springer-Verlag, pp. 204-229.
10. DIMATTEO, M.R. & HAYS, R. (1981) Social support and serious illness. In: B.H. GOTTLEIB (Ed.) Social networks and social support in community mental health. Beverley Hills Ca, Sage, pp. 117-148.
11. WALLSTON, K.A. & WALLSTON, B.S. (1983) Who is responsible for your health ? The construct of health locus of control. In: G. Saunders & J. Suls (Eds.) Social psychology of health and illness. Hillsdale N.J., Erlbaum, pp. 65-95.
12. WORTMAN, C.B. (1984) Social support and the cancer patient: conceptual and methodological issues. Cancer, 53 (supplement, whole), pp. 2339-2359.
13. BORNE, H.W. VAN DEN & PRUYN, J.F.A. (1985) Lotgenoten bij kankerpatienten, Assen/Maastricht, Van Gorcum.
14. DYK, R.B. & SUTHERLAND, A.M. (1956) Adaption of the spouse and other family members to the colostomy patient. Cancer, 9, pp. 123-138.
15. DEROGATIS, L.R. (1980) Breast and gynaecologic cancers: their unique impact on body image and sexual identity in women. In: J.M. Vaeth (Ed.) Frontiers of radiation therapy and oncology, 14, Basel, Karger S., pp. 1-11.

16. BARD, M. & SUTHERLAND, A.M. (1952) Adaptation to radical mastectomy. Cancer, 8, pp. 656-671.
17. VINCENT, C.E, VINCENT, B., GREISS, F.C. & LINTON, E.G. (1975) Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
18. BULLARD, D.G., CAUSEY, G.G., NEWMAN, A.B., ORLOFF, R., SCHANCHE, K. & WALLACE, D.H. (1980) Sexual health care and cancer: a needs assessment. In: J.M. VAETH (Ed.) Frontiers of radiation therapy and oncology, 14, Basel, Karger S., pp. 55-58.
19. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., M.W. HENGEVELD, A. STANEKE (1991) Sexual functioning after ostomy. Sexual and Marital Therapy. Accepted for publication.
20. JANSSENS, J. & WIJMA, K. (1982) Seksuele problemen bij vrouwen die mutilerend behandeld zijn voor kanker; de noodzaak voor een onderzoeksproject. Kanker, 3, pp. 15-16.

Chapter 2

A conceptualization of sexual functioning; social, psychological and somatic aspects

The aim of this chapter is to provide an introduction into the sociological, psychological and somatic theories on human sexuality, used in this study. Although efforts were made to make the text, as much as possible, accessible for physicians as well as for psychologists, the use of some jargon could not be avoided.

2.1 Introduction: views on human sexuality

"Eating and copulating have always been of interest to people and are likely to remain so. Each of these behaviours satisfies a basic biological need - eating, the survival of the individual; copulating, the survival of the species".[1] Given the importance of these basic conditions for survival, it is a logical consequence that every society is structured around at least these two central themes: the way the production of food is arranged and the way sexuality is arranged. With regard to sexuality, large differences in arrangements exist between different cultures and times. Whereas a quick orgastic response of the male is nowadays seen as a "dysfunction", the same response in the female is seen as a manifestation of sexual competence; whereas some decades ago masturbation was seen as pathological behaviour leading to dreadful diseases, nowadays it is being advocated as a healthy way of reaching psychological growth. Observations such as these have led to the conclusion that not only sexual behaviour itself varies with the course of time but that (scientific) theories about sexuality are changing too and merely reflect contemporary views on human nature in general.[2-4] Although sexuality might be regarded as a biological need for the species to survive, this does not mean that sexuality is also a biological need for all individuals. It has never been shown that abstaining from sexual behaviour has a negative impact on an individual's health status or his (biological) survival.[4] However, since it has become clear that human sexual behaviour serves many more functions than procreation alone, especially social functions,[5] it can be hypothesized that sexual functioning plays an important role in social survival. This means that a distinction must be made between sexuality as a socio-historical process and sexuality as a process belonging to the domain of individually experienced lives.

Unfortunately little theoretical work has been performed during the last decades to bridge this gap between the socio-cultural and psychic approach to sexuality. An interesting exception, however, is the work by Simon and Gagnon.[6] In their essay about sexual scripting, they build on earlier scripting theories (e.g. Bakhtin[7]) which will therefore be briefly discussed. The scripting theory refers to social behaviour in general (and not explicitly to sexual behaviour). Therefore first a general introduc-

tion to this theory will be given followed by a paragraph in which the theory is applied to sexual behaviour.

2.2 Scripting theory

Just as language can be seen as a precondition for speech,[8] most types of social behaviour more often than not unfold according to systematic arrangements. For behaviour to occur, these systematic arrangements, also referred to as "scenarios or scripts", take place on three different levels: a cultural level, an interpersonal level and an intrapsychic level.

Cultural scenarios are the instructional guides that exist at the level of collective life and essentially instruct as to the requirements of specific roles e.g. how to behave as a male or a female, as a physician or a psychologist. The very possibility of a failure in congruence between how to behave as e.g. a physician or psychologist and how YOU behave as a physician or psychologist, male or female, in a concrete interactional situation, must be solved at the level of *interpersonal scripting*. This transforms the social actor, from being exclusively an actor playing his role, into a partial script-writer. He or she becomes involved in shaping the materials of relevant cultural scenarios into scripts for context-specific behaviour. The need to script one's own behaviour and the behaviour of others asks for flexibility and alternatives at the *intrapsychic level*. By using internal dialogues, the process of acting and play-writing can be rehearsed over and over again and modifications can be made if necessary. At this intrapsychic level, oneself and others become interchangable; the person him/herself verbalizes and acts out the wishes and desires of others and others verbalize and act out the desires of the individual. In this barely conscious process, fantasy and reality are adapted to each other and cognitive structures or schemata are changed, expanded or created. Scripts can be regarded as chains or clusters of cognitions referring to the same kind of situations.

The consequence of this scripting process is that norms and values of collective social life are linked to individual life. What is experienced as originating in the deepest recesses of the private self, such as e.g. sexual desires and fantasies, is in fact closely connected to social life.

2.3 Sexual scripts

According to Simon and Gagnon, the very concept of the scripting of sexual behaviour implies a rejection of the idea that sexuality represents a very special, if not unique, quality of motivation. From a "scripting perspective", sexuality is not viewed as an intrinsically significant aspect of human behaviour; rather, it views sexuality as becoming significant either when it is defined as significant by collective life (socio-genic significance) or when individual experience or development assign a special significance to it (ontogenic significance).[9] This means that the motivation to perceive and respond in sexual terms is closely linked to what is

essential in a given setting. Cultural scenarios not only specify appropriate objects, aims and desirable qualities of self-other relationships, but also instruct as to what, where and when people are supposed to be doing and feeling things. Interpersonal scripting, representing the actor's response to the external world, draws heavily on cultural scenarios, involving symbolic elements expressive of such scenarios. An example of such a sexual scenario is given by Frenken[10] "There is a hetero-sexual tendency towards an adult partner of about the same age, not family related, within a monogamous and permanent relationship in which intravaginal intercourse takes place directed towards love and procreation". Within a certain range which depends on (sub)cultural variables, such as social class, religion, age, and so on, a number of variations to this scenario can be identified. The most current conceptions of sexual behaviour imply a potential for sexual response that elicits and sustains sexual arousal and, at times, makes orgasm possible.

This potential to respond with a high level of emotional involvement, i.e. sexual arousal, can be explained by hypothesizing the transformation of the object into a participating "other", which in turn, often requires the recognition of the other as another self. For both self and other, the sexual act often represents an act of offering and possessing that which can only rarely be offered and possessed: the intrapsychic experience of another person or "two become one".

In the most pragmatic sense, sexual scripts must solve two problems. The first is gaining permission from oneself to engage in desired forms of sexual behaviour. The second problem comprises gaining access to the experiences that the desired behaviour is expected to generate. For example, for many men's self-esteem, it is important that their partner reaches orgasm during sexual interaction. To be able to achieve this personal success, these men must, in the first place, give themselves permission for sexual interaction with their partner and, in the second place, make their partner experience an orgasm which can be attributed, by them, to their manipulation of the situation. In fact, this requires a very high level of social skill. It is not enough that one person acts according to the wishes of the other, but he or she also has to react emotionally according to the will of the other. Especially the latter requires that the actor's experience becomes contingent not only to what their partner appears to be doing, but also to what their partner appears to be experiencing.

2.4 Sexual behaviour

Wanting something is one thing, but getting it is another. In order to realise his or her sexual desires, the person must be able to behave or function sexually in an appropriate way. According to Bancroft[11] sexual functioning is a prime example of a psychosomatic process. This is schematically illustrated in the "psychosomatic circle of sex".

Cognitive factors and the sensory input from touch, influence our fundamental sexual system in the limbic system and related centres in the spinal cord. This in turn is responsible for the genital and general body changes that follow. Awareness of these body changes can be either exciting or not exciting or even provoke anxiety.

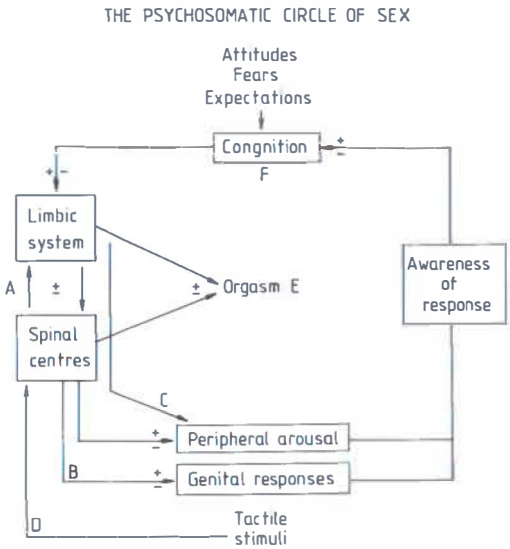


Figure 1 The psychosomatic circle of sex (after Bancroft[11]).

Central and peripheral arousal whilst interrelated, are potentially independant of one another. At each point in the circle it is therefore important to recognize the existence of both excitatory and inhibitory mechanisms. Cognitive factors and sensory information can be distinguished, each referring to a different conceptual background, although they are part of the same system and to a large extent intertwined.

2.4.1 Cognitive factors

Within the cognitive tradition of Dutch sexology, the social learning theory (SLT) plays an important role[5,12-15] and corresponds to a large extent with the scripting theory. Therefore the SLT was chosen as the theoretical background for sexual behaviour in this study and will be discussed here in more detail.

As the name suggests, in this theory behaviour is regarded as a complex cluster of learned phenomena rather than the result of biologically-determined habits. The main architects of the SLT are Wolpe,[16,17] Bandura,[18,19] Rotter,[20] Mischel[21,22] and to some extent Eysenck.[23]. The position of the SLT with regard to the psychoanalytical view and the behavioural view has been described by Maddi[24] as being both partially similar but also partially contrasting. Similar to the psychoanalytical view, the SLT emphasizes the importance of mental functioning. In contrast to Freud, however, it is not the unconscious wishes, impulses and conflicts that are seen as the major determinants of behaviour, but rather cognition, or information processing, or thought that is hypothesized as being rational and logical according to the SLT.[24]

Although the SLT is commonly regarded as behaviouristic, there are also important differences between de SLT and traditional behaviourism. First, there is the

assumption that learning can take place without the "pupil" emitting a response and receiving a positive or negative response for it, and second, the paramount importance in learning that is attributed to cognition, which is internal and not directly observable. According to the SLT, people mainly and commonly learn by observing others behaving in a particular way, which can be very irrational and illogical, in response to a particular stimulus. Then, when the observer is in such a situation himself, he is likely to behave in the same way as he has observed. The person observed has served as a "model" for imitative learning on the part of the person observing. The cultural scenario has become an interpersonal and intrapsychic scenario. This point of view regards cognition, or information processing, or thought as being very active and important.

Especially Rotter[20] has tried to gain an insight to the probability that a particular kind of behaviour will occur. He calls this probability the "behaviour potential". For Rotter behaviour potential is a function of both the expectancy that reinforcement will follow the behaviour and of the perceived value of the expected reinforcement. The emphasis on expectancy and perceived value reflects the cognitive orientation of Rotter. Expectancies and perceived values are internal mental events, which jointly determine whether or not action takes place. Furthermore, it is important to recognize that Rotter employs a subjective rather than an objective basis for predicting behaviour. In other words, if you wish to understand why humans behave or fail to, you must refer to their own individualized view of the world, which Rotter calls "the psychological situation". Individual differences in expectancies and values are not regarded to stem from instincts or underlying motives but rather from differences between previous experience; the value that a person places on reinforcement, reflects its actual utility in that person's past (cf. sociogenic and ontogenic significance). This does not mean that by knowing someone's past, one can fully predict someone's future behaviour.

Rotter[25] asserts that: "People's probability statements and other behaviours relating to the probability of occurrence of an event, often differ systematically from their actuarial experience with the event in the past". According to Maddi[24]:" A variety of factors are regarded to influence one's probability estimates away from objective occurrence. Among these factors are the way in which a situation is categorized, various patterning and sequential considerations, the uniqueness of events, the degree of generalisation that occurs and how the person perceives causality. These factors are not meant to be derived from the person's reinforcement history in any precise way. Rather they are best understood as cognitive commitments or decisions that interact with the objective frequency and utility of reinforcements to produce each person's particular expectancies and values, or his psychological situation. It is this psychological situation that determines the relative likelihood of various actions he might take in the future".[24]

2.4.2 Learning sexual behaviour by means of scenarios and scripts

In combination with Simon and Gagnon's sexual scripting theory, Rotter's social learning theory leads to an interesting model for sexual behaviour.

By means of modeling, people learn which situations are to be interpreted as sexual, which motivational states, corresponding with these situations, are to be labeled as sexual motivation and which sexual behaviour has to be performed as a response to this specific situation. Cultural scenarios are internalised and transformed into interpersonal and intrapsychic scenarios by means of learning and more specifically by modeling. During this process, people also learn that sexual behaviour can serve many more purposes than relief of sexual tension and lustful feelings. Sexual interactions are also regarded as signs of social, gender and moral competence.[5,25] In fact, people's first answer to the question: "What is the most pleasurable aspect of sexuality?" is not orgasm or sexual lust, but the experience of intimacy, the emotional and physical closeness with their partner.[26-31] Of course, experiencing feelings of sexual lust and orgasm is also regarded as an important aspect of sexuality, in particular by men, but this aspect comes in second place.

The results indicate that sexuality should be regarded as the universal set of at least two subsets: intimacy and sexual arousal. There is a partial overlap between these subsets. Being emotionally and physically intimate with each other can be sexually arousing and being sexually aroused together is often perceived as an intimate experience. However, these subsets might also be complementary or even conflicting. Many people experience sexual interactions with ambivalent feelings.[5]

These results make it clear that the meaning of sexuality cannot simply be equated with experiencing sexual arousal and that, therefore, the evaluations of sexual functioning in terms of sexual arousal and orgasm are restricted in their value.

2.4.3 Sexuality as a subjective experience

Another important aspect of the evaluation of sexual functioning to be mentioned here is that, according to the sexual scripting theory and the SLT, sexual (dis)satisfaction can only be a subjective criterium. Frenken[12] defines sexual dissatisfaction as the discrepancy between the individual's "ideal" and "real" sexual experiences which excede certain, again individually determined, limits.

Unfortunately, very little empirical research data, based on cognitive theories, exist on the voluntary control of emotions. In laboratory studies on the voluntary control of sexual arousal, however, the importance of cognitive processes for the elicitation of sexual arousal was demonstrated by the inhibitory effect of cognitive distraction.[32] Anxiety either increased sexual arousal or had no effect on functional subjects. In dysfunctional subjects, anxiety had an inhibitory effect. Furthermore, it has been reported that sexual arousal in response to erotica was fascilitated when subjects perceived themselves as being in control (dominance) of the sexual interaction.[33,34]

2.4.4 Summary

Ideal sexual experiences are based on the slow changing process of intrapsychic scripting, which in turn depends heavily on past experiences. Whether the individual succeeds in realizing his or her desires depends, on a psychological level, on the presence or absence of psychological capacities to perform sexually in such a way that it gives access to these ideal experiences. Important psychological, although

somewhat speculative, determinants are: past experiences, cognitive distraction, anxiety and dominance. The subjective evaluation of sexual functioning can be seen as the outcome of a cognitive process in which ideal sexual experiences and real sexual experiences are weighed against each other.

2.5 The Female Sexual Response, physiological aspects

2.5.1 Introduction

In order to understand why gynaecological cancer treatment may affect sexual functioning, one needs a basic knowledge of the female sexual response cycle and the physiological phenomena contributing to the subjective experiences during sexual arousal.

2.5.2 The concept "sexual response"

The concept "sexual response" referres physiologically to changes in the body and more specifically to changes in the genital organs during sexual arousal. These changes can take place during REM-sleep, during erotic phantasies or dreaming, during masturbation or during sexual interaction with the partner. The most characteristic aspect of the sexual response is that this response is different for every individual. Nevertheless useful conceptual models for the sexual response are available.

Masters and Johnson[35] observed the anatomical and physiological aspects of human sexual responding and quantified them into the "sexual response cycle". They proposed that the cycle for normal healthy individuals had relatively distinct phases, including excitement, plateau (in which arousal remains at a constantly high level), orgasm and resolution. Others have elaborated on this model by including an additional preliminary stage, sexual desire[36] and two extra conceptions, the interaction phase and the solo phase.[37,38] The Human Sexual Response, according to todays' standard, for men and women is depicted in Figure 2.

The horizontal axis represents the course of sexual response against time and the vertical axis the level of "sexual tension",[35] "erotosexual arousal",[40] "sexual arousal",[11] or "central arousal".[41] In fact, erotosexual arousal is the subjective experience that, according to Money,[40] "ensures a unity between that which takes place between the ears and that which takes place between the groins". Originally Masters and Johnson[35] proposed a sexual response cycle for men and women separately. However, this concept of the sexual response has been abandoned.[42]

The interaction phase in the sexual response cycle includes the excitement phase, part of the plateau phase and the resolution phase. In the interaction phase people that make love can or will be focussed on each other: interaction. In the solo phase people turn inwards and concentrate on their own feelings. The solo phase includes part of the plateau phase and the orgasmic phase. In the practice of sex therapy, especially with orgasmic dysfunction, the concept of the sexual response appeared to be of great value.[43]

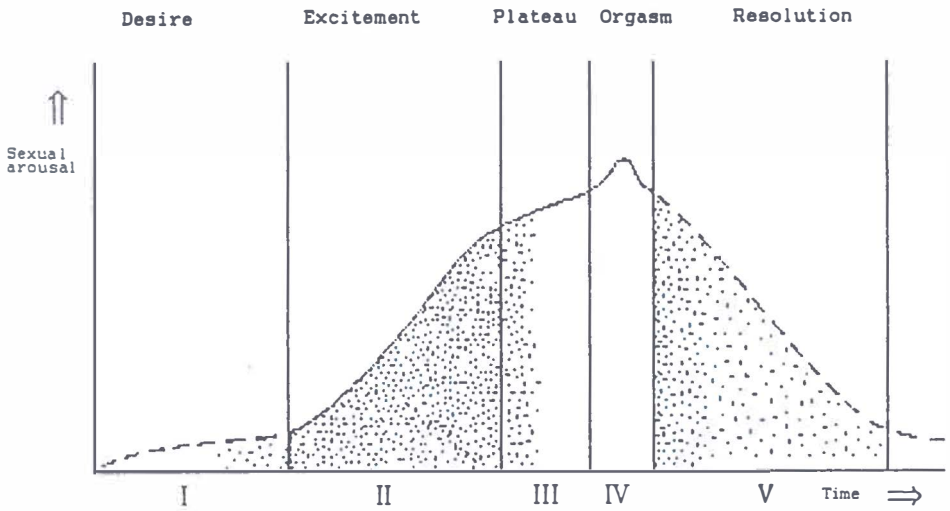


Figure 2 A schematic Sexual Response for men and women, according to todays' standard (after Slob et al.[39]).

Although this model of the sexual response cycle has its uses, especially in the educational and therapeutic field, it also threatens to obscure any further understanding of the sexual response and sexual dysfunction.[44] Masters and Johnson[35] have described the human sexual response as a fixed sequence of four phases. According to Masters and Johnson, these phases can be distinguished on the basis of the occurrence of discrete somatic responses. But this theory has been criticized on the grounds that intra and interindividual differences in the course of the sexual response are too wide; integration into a sequence of four phases is not possible.[42]

Kaplan[45] originally distinguished only two phases: excitement and orgasm. This distinction is based in part on physiological evidence and in part on how, according to Kaplan, sexual dysfunctions cluster together. Later, Kaplan[36] introduced a third phase: the phase of sexual desire. This is the phase in which sexual feelings become manifest, "probably by activating a cerebral nerve system".

Bancroft[11] made a distinction between sexual arousal and sexual orgasm. This distinction is based on discrete physiological responses and discrete subjective experiences, which occur during orgasm and not during sexual arousal. He divided sexual arousal into sexual appetite or drive, central arousal, genital response and peripheral arousal.

Bancroft's distinction remains very close to observable phenomena. The only exception is the introduction of the concept "sexual appetite or desire". This is defined as "the motivating force behind our sexual behaviour in addition to our intrinsic arousability, which influence the strength of the response to sexual stimulation". Dekker,[41] in his thesis on the voluntary control of sexual arousal, hesitates to adopt this concept, because nothing is gained by using it: "the danger of using the concept of sexual appetite, drive, motivation or desire is that of implicitly or explicitly

assuming that a unitary process drives our sexual behaviour. However, so far, there is really nothing in the literature that would justify the use of a concept like sexual desire, motivation etc., in the sense of a unitary driving force behind sexual arousal and behaviour".

For the formation of this chapter, Dekker's concept is adopted because to our opinion his concept seems to be the most distinct. He distinguishes:

I. central arousal (including neural and cognitive processes and the experience of sexual arousal and desire),
II. genital responses,
III. peripheral extragenital arousal, and
IV. factors influencing central, genital and peripheral arousal and arousability.

2.5.3 Central arousal

The psychophysiological nature of central arousal that may accompany the genital and other autonomic responses to sexual stimuli, is hardly understood. Although (or perhaps: because) sexual arousal is a pleasurable and intensive experience for most individuals, no system has been developed to describe this experience. In verbal reports (e.g. Hite[29,46]) subjects report being aware of genital and extragenital sensations. These sensations are pleasurable and lustful. In addition subjects report a general feeling of excitement, (sexual) arousal and lust and the desire for more of this. However, various other emotional states can be experienced as well, e.g. fear or a feeling of guilt.

Central arousal might be related to the limbic system status; this has been indicated by the electric stimulation in a number of sites in the limbic system of squirels and rhesus monkeys.[47] For humans no such data are available, the only evidence being rather inconclusive clinical data,[48] e.g. the hypo and hyper-sexuality desire disorders of temporal-lobe epileptics.[49] It has also been suggested that central amine neurotransmitters are involved in central arousal.[50] This has been inferred from the decrease or increase in sexual behaviour seen in patients with affective disorders, such as depression and mania, in which the functional availability of neurotransmitters is believed to be involved.

Androgens are hypothesized as providing the hormonal basis for sexual desire in the male. It is known from male to female transsexuals, that the libido is reduced because of antiandrogens while the erectile capacity during sexual arousal hardly changes.[51] From laboratory studies, quite often with hypogonadal men, it has become obvious that testosterone significantly increases sexuality, i.e. sexual thoughts, sexual acts, orgasm, energy, compared to no treatment or placebo.[52,53]

Which specific steroids are involved in female sexual functioning is uncertain. So far, studies on cyclic changes in sexual interest produced inconsistent results.[39] A minimal amount of oestrogen may be required for sexual interest, enjoyment and orgasmic capacity.[54] It appears that androgens rather than oestrogens are the critical factor in terms of maintenance of sexual interest both before and after menopause.[55,56] Androgen replacement therapy following oophorectomy has revealed an enhancing effect with regard to sexual desire, thoughts and phantasies, as well as on

rates of coitus and orgasm.[57,58] Female to male transsexuals, receiving androgens, report an increase in their sexual desire.[51] Progesteron may have an inhibitatory effect on central arousal.[54]

2.5.4 Genital responses in the female

In the female genital sexual response, two major physiological processes can be distinguished: vasocongestion and myotonia.

The vasocongestive aspect of the genital response in the female

Sexual excitation in the female is characterized by the appearance of vaginal lubrication, which is produced by an increase of the arterial flow to the vaginal wall, leading to the transudation of fluid. This vaginal response to erotic stimuli in females is the most comparable response to erection in the male, both in its timing and in its susceptibility to psychological factors. Masters and Johnson[35] described the initial vaginal response as a moistening or lubrication of its wall, starting 10 to 30 sec after the onset of sexual stimulation. They attributed this "sweating" phenomenon to the transudation of fluid, resulting from a marked dilation of the venous plexus which encircles the entire vaginal barrel. It is of interest that the transudate reaches maximum level at an early stage in sexual response and that, after prolonged stimulation, either by masturbation or coitus, the vagina may become relatively dry.[35,59] This, presumably, would be in spite of continuing vasocongestion and suggests that whatever the mechanism might be, it is of limited duration.

The "porosity" of the vaginal epithelium may be dependent on normal levels of oestrogen acting locally.[60] It is a remarkable fact that if an artificial vagina is created surgically or by other means in women with a congenital absence of the vagina, the tube of epidermis used for the purpose will eventually start to form "vaginal transudate" in response to sexual stimulation, which is apparently similar to that of normal vaginal tissue.[35]

The variable degree of involution that occurs in the uterus, vagina and labia of post-menopausal women is mainly due to oestrogen deficiency. The epithelium of the vaginal wall becomes thinner. The ability to produce transudate is also reduced, although whether this is the result of epithelial thinning or to some reduction in vascularisation of the vaginal wall is not known. There is abundant clinical evidence that these changes respond to either systemic or local oestrogen treatment.[61] Oestrogens appear to be important for maintaining vaginal lubrication and for the perception of sexual arousal, but not for determining vaginal vasocongestion.[62] There is good evidence that in low estrogen situations, androgens may promote the growth of vaginal epithelium as well.[56,63] Also, less vaginal atrophy is apparent in sexually active woman than in sexually inactive woman.[35,56] As is also the case with erection in the male, the precise vascular mechanism of vaginal response is unclear. Masters and Johnson[35] refer to "dilation of the veins" and a "fulminating vasocongestive reaction" around the vagina. But it is not clear to what extent this is due to 1) arterial dilation which depends on the relaxation of special arteriolar valves or "polsters", 2) venous entrapment by the closure of muscular venous valves, or 3) a combination of both. However, valvular mechanisms in both genital arteries and veins in men and in

women have been described.[64,65] The effect of vasocongestion in men and women is certainly comparable: there is swelling of the labia and of the vaginal wall which consequently elongates and changes from its normally "collapsed" state into being slightly patent. The outer third of the vagina in particular becomes engorged and narrows, thus forming a "turgid cuff". The inner two thirds of the vagina becomes elongated and widens, a phenomenon called "ballooning".

Another effect of vasocongestion is an increase in the diameter of the clitoral shaft and length. With prolonged stimulation the glans clitoris retracts under the clitoral hood. The labia majora increase in size and move away from the vaginal opening. The labia minora also become engorged and a little everted. With increased arousal the labia minora change from bright red to a deep purple colour. The uterus also becomes engorged and increases in size, at the same time rising in the pelvis, thus producing the "tenting effect". This displacement probably results from contraction of the many plain muscle fibres in the parametrial tissues supporting the uterus and upper vagina.

Some investigators describe a circumscript vasocongestive erotic sensitive area on the anterior vaginal wall close to the urethra. This area can be detected during sexual arousal and is referred to as the "G-spot".[66,67] Even a connection between stimulation of the "G-spot" and a specific kind of orgasm, the so-called "uterus orgasm", has been suggested.[66,68] However, the existence of a circumscript vasocongestive area on the anterior vaginal wall during sexual arousal cannot be confirmed unanimously.[69,70] Other specific erotic sensitive areas on the vaginal wall with orgasmic potential in themselves have also been detected.[66,67,69,70] According to Hoch,[70] the entire extent of the anterior wall of the vagina (rather than one specific spot), as well as the more deeply situated tissues, including the urinary bladder and urethral region, are extremely sensitive, being richly endowed with "sexual nerve endings". Data underscoring previous anatomical and clinical research findings regarding the sensitivity of the anterior vaginal wall have been provided (this thesis).

The myotonic aspect of the genital response in the female

Of the various components of sexual response, the orgasm remains the most enigmatic. Neuromuscular activities prevail, involving the whole body. Kinsey et al.[72] describe orgasm as an "explosive discharge of neuromuscular tension at the peak of sexual response". They stress the considerable degree of individual variation in orgasms, especially in the intensity of excitement and neuromuscular responses that occur. Some individuals may be close to unconsciousness at the time of orgasm. Undoubtedly, for many there is blunting of awareness and the loss of control of one's body with its resulting unvoluntary noises, grimacing and convulsions. In fact it is a reflex, and, like all other reflexes, it can be stimulated or inhibited by direct sensory input or impulses from the cerebrum.

Masters and Johnson[35] have described the genital responses associated with female orgasm in some detail. Retraction of the clitoris occurs prior to orgasm. As a result the clitoris becomes less palpable. The outer third of the vagina becomes markedly swollen, reducing the lumen by at least a third. This is what Masters and Johnson call the "orgasmic platform" as it is the site for the response that they be-

lieve to be the essence of the female orgasm: an initial spasm of the muscles surrounding the orgasmic platform followed by a series of rhythmic contractions.

These are usually five to eight in number, initially with an interval of 0.8 sec between each contraction. The subjective experience of the onset of orgasm precedes this by a few seconds. Synchronous contractions of the anal sphincter occur in a proportion of women.[73] Uterine contractions occur as well and are mentioned to be of importance for the sexual response by 15% (always) to 37% (sometimes) of the women.[74] It is unknown whether orgasm is possible without muscular contractions.

One of the most intruiging debates in the field of human sexuality has concerned the nature of female orgasm. Starting with Freud's assertion that continuing reliance on clitoral stimulation in order to experience orgasm is a sign of immaturity which indicates the failure of "clitoral-vaginal transfer", the battle has waged ever since and still continues. Kinsey et al.[72] marshaled considerable evidence that the vaginal walls were insensitive to touch, in marked contrast to the clitoris and labia majora. They pointed out the biological impossibility of the psychoanalytic viewpoint as well as the lack of evidence.

Although their criticism was trenchant, they perhaps underestimated the role that pressure rather than touch might play in the vagina and cervix. Masters and Johnson[35] went on to report that either direct or indirect stimulation of the clitoris is always necessary for orgasm and that the physiological changes that accompany it are the same whatever the method of stimulation. Although it may not have been their intention, this has led to the conclusion that there is only one type of female orgasm.

Evidence is accumulating that there are more types of female orgasm.[75-76] Singer[77] has discussed the evidence in some detail and reached the firm conclusion that there are at least two basic patterns which may combine: he calls these "vulval" and "uterine". The vulval orgasm depends on clitoral stimulation, occurring either from direct stimulation or coitus and is manifested in vaginal contractions. The uterine experience is characterized, he suggests, by more marked emotional reactions and apnoe, it is not associated with vaginal contractions and is dependent on uterine or visceral buffeting that occurs with the deep penetration of coitus. He makes the notable point that the apparent absence of the uterine type of orgasm in Masters and Johnson's experimental data could reflect the difficulty in attaining the appropriate psychological requirements in the laboratory, the vulvar orgasm being much easier to produce.

Perry and Whipple[68] describe two pathways in sexual response. The first reflex arc includes the clitoris as its major source of stimulation, the pudendal nerve as its pathway and the bulk of the pubococcygeus muscle (or "orgasmic platform") as the major manifestation of myotonic build-up and discharge during orgasm. The second reflex arc includes the "G-spot" as its major source of stimulation, the pelvic nerve as its major pathway and the musculature of the uterus, the bladder, the urethra and the proximal portions of the pubococcygeus muscle as its major myotonic manifestation. In the spinal cord (S2-4), the pudendal and pelvic nerves partially overlap, providing some physiological basis for interaction between the two reflex arcs.[78] Conceptualizing uterine and vulval orgasm as a continuum rather than discrete

categories, Perry and Whipple[68] state that "it is possible to have orgasms which are purely one or the other extreme, but in fact most orgasms of most people most of the time are blended".

Scientific inquiry into the question of whether or not some women emit a fluid ("ejaculate") upon orgasm definitely revealed the existence of this phenomenon in about 10% of the women.[66,67,70,78,79,80,81] It can occur on tactile stimulation of the "G-spot" and/or clitoris and without tactile stimulation during sleep.[80] Controversy still surrounds the precise mechanism involved. Possible explanations: urine incontinence,[67,82] Bartholin's fluid,[83] excessive transudation,[72,84] intraurethral glands[85-87] So far, all these hypothesis are no more than sheer speculation. Chemical analysis of the "ejaculate" of one experimental person revealed prostatic acid phosphatase, an enzyme characteristically found in prostatic secretion.[78] Another analysis of the "ejaculate" of 6 experimental persons did not reveal elevated levels of prostatic acid phosphatase.[67] The biochemical properties of the substance appeared to be similar to urine. Maybe female ejaculation is simply a more socially acceptable concept than urinary incontinence occurring during intercourse.[88]

2.5.5 Peripheral extragenital arousal

A range of extragenital responses have been reported, primarily by Masters and Johnson.[35] These responses are often weakly correlated with genital and subjective measures of sexual arousal. They are often not specific to sexual arousal, occurring in other arousal states as well.[61,89-92] Also the importance of the non-genital responses for sexual satisfaction is difficult to judge. Among the responses reported are:

- nipple erection in men and women; tumescence of areola and increase in breast size in women;
- a "sex flush", i.e. a rash spreading over the skin;
- increase in general myotonia and spasmodic muscle contractions; contractions in the rectum;
- both increases and decreases in the heart rate;
- increased respiration rate;
- increased systolic and diastolic blood pressure;
- increased sweat gland activity (both skin conductance and galvanic skin responses);
- both increases and decreases in skin temperature;
- changes in EEG activity (laterality), pupil dilation and biochemical changes (among them urinary catecholamines urinary, acid phosphatase and blood hormone levels).

2.5.6 Factors influencing central, genital and peripheral arousal and arousability

A genital response can be produced by a reflex process i.e. as a result of somatic input via reflex centres in the spinal cord and psychologically i.e. as a result of external or internal stimuli, e.g., visual, olfactory, auditory or the imagination, mediated by the brain. Clearly, these two mechanisms normally interact; psychic stimulation will lower the threshold for reflexive stimulation and vice versa. But the potential

independence of these two mechanisms is evident from results of spinal cord or sympathetic outflow injury.[86,93]

The interaction between central response, genital response and peripheral response is accomplished through the nervous system.

The human nervous system consists of a central nervous system, the brain and spinal cord; a peripheral somatic nervous system, which includes the cranial and spinal nerves; and an autonomic or unvoluntary nervous system. Through peripheral nerves, the brain and spinal cord must receive all incoming (afferent) sensory information and transmit all outgoing (efferent) motor commands. The autonomic nervous system is primarily concerned with the regulation of visceral activities, but contains facilities for sensory information as well.[94,95] Most of the viscera, including the genital organs, receive a double autonomic innervation, sympathetic and parasympathetic, the effects of the two being as a rule antagonistic.

Nerve cells of the afferent somatic nerves are located in the spinal ganglia (=aggregation of nerve cells) and nerve cells of the efferent somatic nerves in the spine.

Unlike peripheral somatic nerves, the transmission of autonomic nerves always involves two different neurons. The first neuron, situated in the brain or spinal cord, sends its axon as a preganglionic fiber to some autonomic ganglion, situated in the sympathetic trunk or pelvic plexus, but the linking from preganglionic to postganglionic nerve can take place in or near the target organ as well. For the change over from one nerve to another and for the nerve endings (receptors), a wide range of neurotransmitters are involved: (nor)adrenalin, acetylcholine, vaso-active intestinal polypeptide (VIP), somatostatine and encephaline.[96-100] Evidence is accumulating that particularly vasoactive intestinal polypeptide (VIP) plays a prominent physiological role in sexual arousal.[101] The dense innervation of blood vessels and smooth muscle by nerve fibers containing VIP in both the vagina and clitoris, together with the putative neurotransmitter role of VIP in noncholinergic, nonadrenergic vasodilatation and smooth muscle relaxation, lead to this assumption. During sexual arousal the VIP concentration in peripheral venous blood increases significantly and in women the infusion of VIP intravenously, leads to a dose-related increase in vaginal blood flow.[102] Little is known about the significance of VIP as a neurotransmitter in the pelvic plexus and about its interaction with sympathetic and parasympathetic nerves.

The genitals are richly supplied with sensory nerve endings. Many of them are specialized in type, although their precise function is not fully understood. Some are concentrated around blood vessels and may be important for monitoring vasocongestion.[99] Others may be peculiar to erotic perception. Histological studies have revealed free nerve endings in and near the vaginal epithelium, or forming plexuses around the blood vessels[103-106] and a more intense nerve supply between the bladder and the vaginal wall.[103,106] The clitoris is particularly rich in nerve endings. Between individuals, there is a wide variation in quantity, quality and location of various nerve endings in the genital area, probably accounting for the variation in preference of the location of touch.[103]

The pudendal nerve:

For the genital tract the principal somatic nerve is the pudendal nerve. The pudendal nerve furnishes most of the innervation to the perineum. It contains motor fibers, sensory fibers and postganglionic sympathetic fibers.[94,107] It runs from S2,3, and 4 through the cauda equina and greater sciatic foramen, crosses the back of the ischial spine, and enters the perineum through the lesser sciatic foramen. It first gives of (1) the inferior rectal nerve and then divides into (2) the perineal nerve and (3) the dorsal nerve of the clitoris.

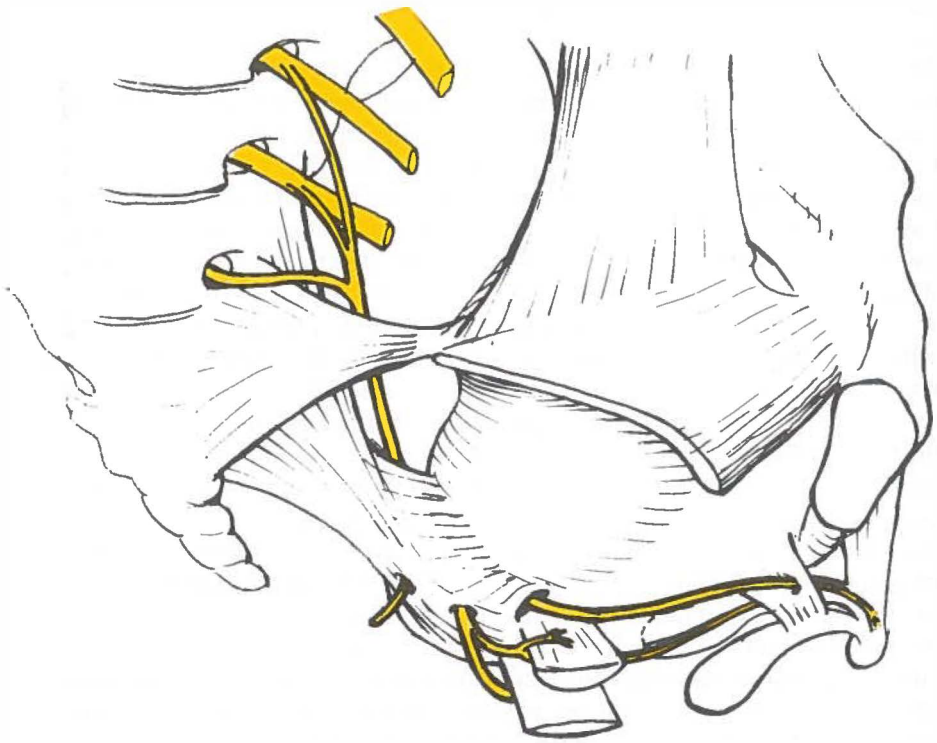


Figure 3 The pudendal nerve and its branches

The inferior rectal nerve supplies the sphincter ani externus, the skin around the anus and the lining of the anal canal as far up as the pectinate line. The perineal nerve helps to supply most of the pelvic floor muscles (the sphincter ani externus, the levator ani, the bulbospongiosus, the isschiocavernosus, the superficial transversus perinei), the bulb of the clitoris and the labium majus. The dorsal nerve of the clitoris supplies the deep transversus perinei muscle, the sphincter urethrae, the corpus cavernosum clitoris and the glans and praeputium of the clitoris. Somatic nerves supplying the genital area, but of minor importance, are the ilioinguinal nerves (L1) and the genitofemoral nerves (L1 and L2).

The autonomic nerves:

The autonomic innervation of the female genital tract originates from T10 - L3 (sympathetic nerves) and from S2 - S4 (parasympathetic nerves). Sympathetic nerves run either through the sympathetic trunk or through the lumbar splanchnic nerves, the superior hypogastric plexus and hypogastric nerves to the pelvic plexus. Parasympathetic nerves also run as pelvic splanchnic nerves (= pelvic nerves) to the pelvic plexus. They join the pelvic plexus only as it begins to fan out in the anterior pelvis (Figure 4).[108]

The female pelvic plexus (= plexus hypogastricus inferior or plexus pelvinus) can be found retroperitoneally adjacent to the rectum and vagina. It forms a plate situated in a sagittal plane that extends ventrally from the sacrum. Its length is about 4 - 6 cm and its width is about 2.5 - 3 cm.[95] The bulk of the plexus is situated very close to the anterolateral aspect of the lower rectum, near the anorectal junction and, like a flat meshed band, is connected to the lateral wall of the upper third of the vagina below the broad ligament. The upper fibres of the plexus usually extend into the cardinal ligament (of Mackenrodt), which forms the tough base of the broad ligament.[109] The ureter lies medially, in close contact with the plexus, whereas the uterus is separated from it by the frontally located parametrium. Para-sympathetic and sympathetic neurons intercommunicate freely in the pelvic plexus.[110] From here connections exist with the rectum, vagina, uterus, bladder and urethra.

The types of fibers reaching a particular organ and the function of these fibers are uncertain in many instances. We do know that sympathetic impulses reach the smooth muscle tissue of the neck of the bladder, urethra, uterus and vascular tissue. Parasympathetic nerves innervate smooth muscle tissue as well and are considered to be particularly important for vasocongestion and lubrication. Bartholin's glands receive parasympathetic impulses.[111] The pelvic floor musculature i.e., the musculus pubococcygeus and the musculus ileococcygeus and also the musculus coccygeus, are innervated by nerves which enter them from within the pelvis.[112] The branches of the musculus coccygeus and the musculus pubococcygeus originate from the anterior ramus S3; the nerve of the musculus ileococcygeus arises from the midportion of the pelvic plexus.[95,113] Afferent nerves travel to the central nervous system via both parasympathetic and sympathetic pathways. Impulses from the uterus, cervix and medial section of the tubes reach the spinal cord via sympathetic pathways at the level of Th12 and L1. Impulses from the ovaries and the lateral section of the tubes reach the spinal cord via sympathetic pathways at the level of Th10,11.

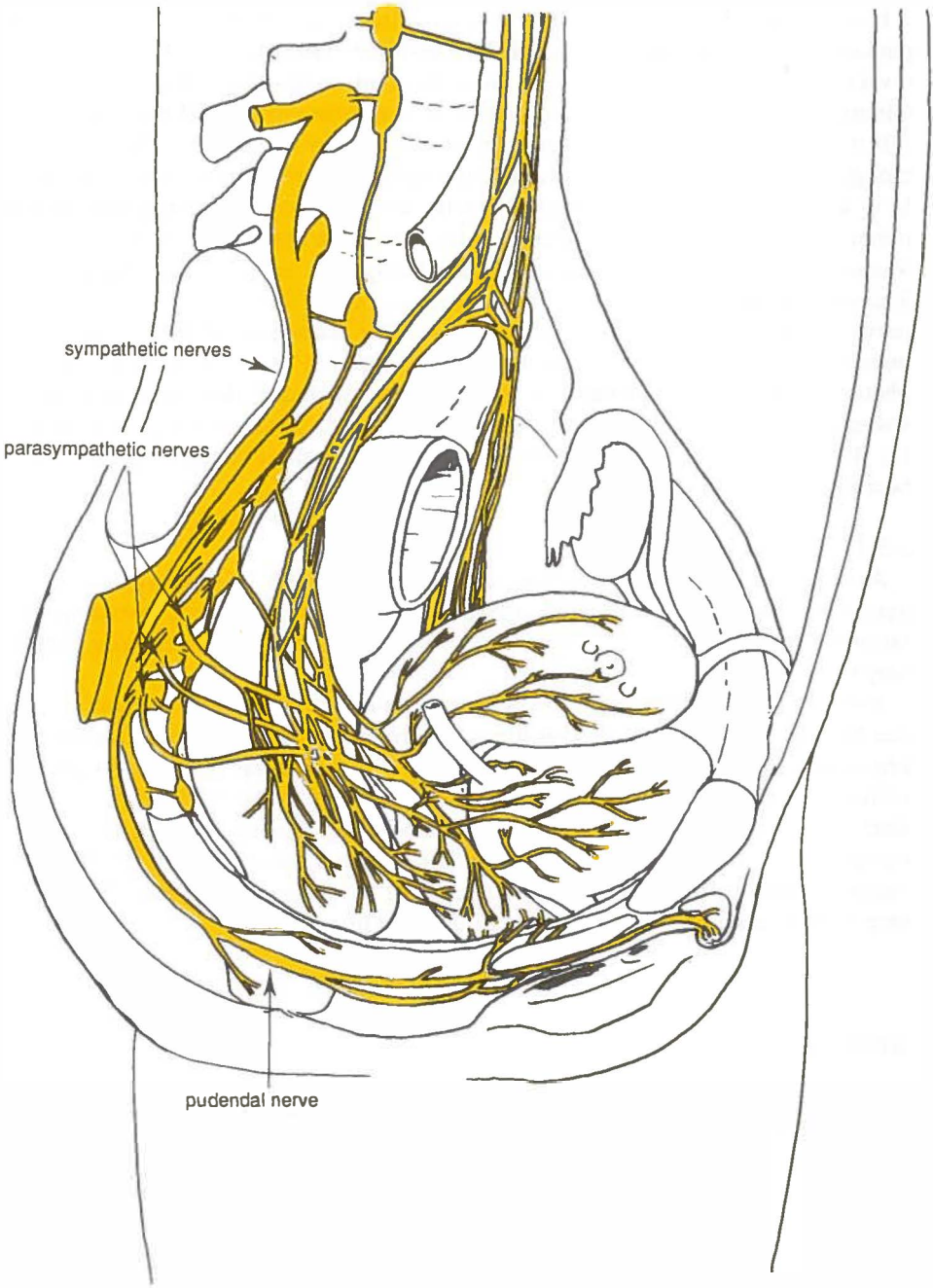


Figure 4 The autonomic innervation of the female genital tract and the pudendal nerve

Impulses from the upper half of the vagina reach the spinal cord via parasympathetic pathways at the level of S2 - 4.

It is speculated that there are two reflex centres in the spinal cord, one parasympathetic reflex centre at the level of S2-4 and one sympathetic reflex centre at the level of Th12 - L1. The upper centre might be involved in vasocongestion on psychic stimulation and the lower centre on vasocongestion on physical stimulation.

It is unknown which mechanisms are involved in the retraction of the clitoris, the elongation and widening of the vagina and the change in the position of the uterus. It is also unknown which muscles exactly are involved during orgasm, at what moment in time and how they interact. Also the exact trigger for orgasm is unknown. Vasocongestion probably induces stimuli through the stretching of muscles.[99,114] These stimuli reach the brain by means of the sensory fibers of the somatic pudendal nerve in particular. Orgasmic pleasure is usually accompanied by contractions of muscles in the genital tract, but it should be realized that it is a central nervous phenomenon as well. Besides, it has not been excluded that hormones are involved.[115] For the uterus, this might be oxytocin or vasopressin and prostaglandins; for the vagina, the catecholamines (in the vaginal wall adrenergic receptors have been demonstrated).

2.5.7 The interaction

As yet, we should not assume like the theoretical models of arousal have encouraged to do in the past, that central arousal and peripheral arousal are linked manifestations of the same process. They are clearly related, but in a potentially complex way.[61]

Because of this complex interaction, one should realize that the sexual response can be selectively damaged by an illness. Moreover, the importance of the different physiological changes will vary from individual to individual, e.g. many women are content not to experience an orgasm, at least not every time.[15,27,28,29,116,117] Therefore, the consequence of negative factors operating at some specific point in the sexual response cycle, also in gynaecological cancer patients, can only be understood by considering their effects on the whole person within her specific relationship or non-relationship and not just at the point of action.

REFERENCES

1. SZASZ, T. (1980) Sex by prescription. New York, Anchor Press/ Doubleday, p. XIII.
2. SCHMIDT, G. (1983) Motivationale Grundlagen sexuellen Verhaltens. In: H. Thöma (Ed.) Psychologie der Motive. Göttingen.
3. FOUCAULT, M. (1976) La volonté de savoir. Parijs, Gallimard.
4. USSEL, J. VAN (1975) De geschiedenis van het sexuele probleem. Deventer, Van Loghum Slaterus.
5. FRENKEN, J. (1976) Afkeer van seksualiteit. Deventer, Van Loghum Slaterus.
6. SIMON, W. & GAGNON, J.H. (1986) Sexual scripts: permanence and change. Archives of Sexual Behavior, 15, pp.97-120.

7. BAKHTIN M. (1981) The dialogic imagination: four essays. In: M. Holquist (Ed.) University of Texas Press Slavic Series, 1, Austin.
8. LACAN, J. (1977) Ecrits, a selection. New York, Norton.
9. GAGNON, J.H. & SIMON, W. (1973) Sexual conduct: the social sources of human sexuality. Chicago, Aldine.
10. FRENKEN, J. (1984) Recente geschiedenis van de seksualiteit. In: A.K. Slob, A. Meulenbelt & J. Frenken (Eds.) Facetten van seksualiteit. Alphen aan de Rijn, Samson Stafleu.
11. BANCROFT, J. (1983) Human sexuality and its problems. Edinburg/London, Churchill Livingstone.
12. FRENKEN, J. (1980) Het voorkomen van seksuele problemen in man-vrouw relaties. In: J. Frenken (Ed.) Seksuologie, een interdisciplinaire benadering. Deventer, Van Loghum Slaterus.
13. VENNIX, P. (1981) Het onvermogen van de heteroseksualiteit. Zeist, NISSO.
14. VENNIX, P. (1983) De ILKS-gedachte en andere operationalisaties. Zeist, NISSO.
15. BRUIJN, G.M. DE (1882) From masturbation to orgasm with a partner: how some women bridge the gap and why others don't. Journal of Sex and Marital Therapy, 8, pp. 151-167.
16. WOLPE, J. (1958) Psychotherapy by reciprocal inhibition. Stanford, Stanford University Press.
17. WOLPE, J. (1969) The practice of behavior therapy. New York, Pergamon.
18. BANDURA, A (1969) Principles of behavior modification. New York, Holt, Rhinehart & Winston.
19. BANDURA, A. & WALTERS, R.H. (1963) Social learning and personality development. New York, Holt, Rhinehart & Winston.
20. ROTTER, J.B. (1954) Social learning and clinical psychology. New York, Prentice Hall.
21. MISCHEL, W. (1968) Personality and assessment. New York, Wiley.
22. MISCHEL, W. (1971) Introduction to personality. New York, Holt, Rhinehart & Winston.
23. EYSENCK, H.J. (1957) The dynamics of anxiety and hysteria: an experimental application of modern learning theory to psychiatry. London, Routledge & Kegan Paul.
24. MADDI, S.R. (1976) Personality theories, a comparative analysis. Homewood, Dorsey Press.
25. ROTTER, J.B., CHANCE, J.E. & PHARES, E.J. (1972) Applications of a social learning theory of personality. New York, Holt, Rhinehart & Winston.
26. JAYNE, C. (1981) A two dimensional model of female sexual response. Journal of Sex & Marital Therapy, 7, pp. 3-30.
27. BELL, B.R. & BELL, P.L. (1972) Sexual satisfaction among married women. Medical Aspect of Human Sexuality, 6, pp.136-144.
28. TAVRIS, C. & SADD, S. (1977) The redbook report on female sexuality. New York, Delacorte.
29. HITE, S. (1976) The Hite-report. New York, MacMillan.
30. GEERAERT, A. (1977) Seksualiteit bij ongehuwde jeugdigen. Leuven, Katholieke Universiteit.
31. FISHER, S. (1973) Understanding the female orgasm. New York, Basic Books.
32. DEKKER, J. (1988) Voluntary control of sexual arousal. Utrecht, OMI.
33. HEIMAN, J.R. (1977) A psychophysiological exploration of sexual arousal patterns in females and males. Psychophysiology, 14, pp. 266-274.
34. GARCIA, L.T., BRENNAN, K., DECARLO, M., MCGLENNON, R. & TAIT, S. (1984) Sex differences in sexual arousal to different erotic stories. Journal of Sex Research, 20, pp. 391-402.

35. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
36. KAPLAN, H.S. (1979) Disorders of sexual desire. New York, Brunner/Mazel.
37. EVERAERD, W., VAN NAERSSEN, L. & COHEN-KETTENIS, P. (1977) Anders denken over seksualiteit. Deventer, Van Loghum Slaterus.
38. EVERAERD,W. & DEKKER, J. (1981) A comparison of sex therapy and communication therapy: couples complaining of orgasmic dysfunction. Journal of Sex and Marital Therapy, 7, pp. 278-289.
39. SLOB, A.K., VINK, C.W., MOORS, J.P.C. & EVERAERD W. (1987) Seksuologie voor de arts. Alphen aan den Rijn/Brussel, Samsom Stafleu.
40. MONEY, J. (1981) The development of sexuality and eroticism in humankind. The Quarterly Review of Biology, 56, pp. 379-404.
41. DEKKER, J. (1988) Voluntary control of sexual arousal, experimental studies on sexual imagery and sexual history as determinants of the sexual response. Utrecht, Dissertation.
42. ZILBERGELD, B. (1982) Mannen en seks. Gent, Masereelfonds.
43. SLOB, A.K. (1988) Endocrine Aspects of Sexuality in the Elderly. In: W. Eicher & G. Kockott (Eds.) Sexology. Berlin/Heidelberg, Springer-Verlag, pp.159-166.
44. BANCROFT, J. (1980) Endocrinology of sexual function. Clinics in Obstetrics and Gynecology, 7, pp. 253-281.
45. KAPLAN, H.S. (1974) The new sex therapy. New York, Brunner/ Mazel.
46. HITE, S. (1978) The Hite Report on male sexuality. New York, Knopf.
47. MCLEAN, P.D. (1976) Brain mechanisms of elemental sexual functions. In: B.T. Sadock, H.I. Kaplan & A.M. Freedman (Eds.) The sexual experience. Baltimore, Williams and Wilkins.
48. HEBBRECHT, M. & VANDEREYCKEN, W. (1984) Hyperseksualiteit vanuit biologisch perspectief. Tijdschrift voor Psychiatrie, 26, pp. 5-16.
49. BLUMER, D. & WALKER, A.E. (1975) The neural basis of sexual behavior. In: D.F. Benson, D. Blumer (Eds.) Psychiatric aspects of neurological disease. New York, Grune & Stratton.
50. MUNJACK, D.L. & OZIEL, L.J. (1980) Sexual medicine and counseling in office practice. Boston, Little Brown.
51. MEYER, W.J., WEBB, A., STUART, C.A., FINKELSTEIN, J.W., LAURRENCE, B. & WALKER, P.A. (1986) Physical and hormonal evaluation of transsexual patients. A longitudinal study. Archives of Sexual Behavior, 15, pp. 121-138.
52. DAVIDSON, J.M., KWAN, M. & GREENLEAF, W.J. (1982) Hormonal replacement and sexuality in men. Journal of Clinical Endocrinology Metabolism, 11, pp. 599-623.
53. SKAKKEBAEK, N.E., BANCROFT, J., DAVIDSON, D.W. & WARNER, P. (1981) Androgen replacement with oral testosterone undecanoate in hypogonadal men: a double blind controlled study. Clinical Endocrinology, 14, pp. 49-61.
54. DENNERSTEIN, L., BURROWS, G.D., WOOD, C.& HYMAN, G. (1980) Hormones and sexuality: effect of estrogen and progestogen. Obstetrics and Gynecology, 56, pp. 316-322.
55. PERSKY, H., DREISBACH, L. & MILLER, W. (1982) The relation of plasma androgen levels to sexual behaviors and attitudes of women. Psychosomatic Medicine, 44, pp. 305-319.
56. LEIBLUM, S., BACHMANN, G., KEMMANN, E., COLBURN, D. & SWARTZMAN, L. (1983) Vaginal Atrophy in the Postmenopausal Woman. The Importance of Sexual Activity and Hormones. JAMA, 249, pp. 2195-2198.

57. SHERWIN, B.B., GELFAND, M.M. & BRENDER. W. (1985) Androgens enhance sexual motivation in females: a prospective, cross-over study of sex steroid administration in the surgical menopause. Psychosomatic Medicine 47, pp. 339-35.
58. SHERWIN, B.B. & GELFAND, M.M. (1987) The role of androgen in the maintenance of sexual functioning in oophorectomized women. Psychosomatic Medicine, 49, pp. 397-409.
59. WAGNER, G. & LEVIN, R.J. (1977) Vaginal fluid. In: A.S.E. Hafez & T.N. Evans (Eds.) The Human Vagina. Amsterdam, Elsevier, pp. 121-137.
60. BANCROFT, J. (1984) Hormones and human sexual behavior. Journal of Sex and Marital Therapy, 10, pp. 3-21.
61. BANCROFT, J. (1983) Human sexuality and its problems. Edingburgh/London, Churchill Livingstone.
62. MEYERS, L.S. & MOROKOFF, P.J. (1986) Physiological and subjective sexual arousal in pre and postmenopausal women and postmenopausal women taking replacement therapy. Psychophysiology, 23, pp. 283-292.
63. BERGER, J. & BOSCHMANN, H.W. (1957) Symposium C: Androgenic effect on vaginal epithelial cells. Acta Cytologica, 1, pp. 70-103.
64. DICKINSON, R.L. (1949) Atlas of human sex anatomy (2nd ed.). Baltimore, Williams & Wilkins.
65. DANESINO, V. & MARTELLA, E. (1975) Modern conceptions of corpora cavernosa functions in the vagina and clitoris. In: T.P. Lowry & T. Lowry (Eds.) The clitoris. St. Louis, Warren H Green, St. Louis.
66. PERRY, J.D. & WHIPPLE, B. (1981) Pelvic muscle strength of female ejaculators; Evidence in support of a new theory of orgasm. Journal of Sex Research, 17, pp. 22-39.
67. GOLDBERG, D.C., WHIPPLE, B., FISHKIN, R.E., WAXMAN, H., FINK, P.J., & WEISBERG, M. (1983) The Grafenberg Spot and female ejaculation: A review of initial hypothesis. Journal of Sex and Marital Therapy, 9, pp. 27-37.
68. PERRY, J.D. & WHIPPLE, B. (1982) Multiple components of the female orgasm. In: B. Graber (Ed.) Circumvaginal musculature and sexual function. Basel, Karger S.
69. ALZATE, H. & LONDONO, M.L. (1984) Vaginal erotic sensitivity. Journal of Sex and Marital Therapy, 10, pp. 49-56.
70. ALZATE, H. (1985) Vaginal Eroticism: A replication study. Archives of Sexual Behavior, 14, pp. 529-537.
71. HOCH, Z. (1983) Letter to the editor, the G-spot. Journal of Sex and Marital Therapy, 9, pp. 166-167.
72. KINSEY, A.C., POMEROY, W.B., MARTIN, C.E. & GEBHARD, P.H. (1953) Sexual behavior in the human female. Philadelphia, Saunders.
73. BOHLEN, J.G., HELD, J.P., SANDERSON, M.O. & AHLGREN, A. (1982) The female orgasm; pelvic contractions. Archives of Sexual Behavior, 11, pp. 367-386.
74. THURKOW, F.G. (1985) Hoe denken vrouwen er zélf eigenlijk over? Een exploratie van de lichaams- en genitale beleving van vrouwen in privé en medische situatie. Groningen, Doctoraalscriptie Rijksuniversiteit.
75. FOX, C.A. & FOX, B. (1971) A comparative study of coital physiology, with special reference to the sexual climax. Journal of Reproduction and Fertility, 24, pp. 319-336.
76. FISHER, S. (1973) The Female Orgasm. New York, Basic Books.
77. SINGER, I. (1973) The Goals of Human Sexuality. London, Wildwood House.
78. ADDIEGO, F., BELZER, E.G., COMOLLI,J., MOGER,W., PERRY, J.D. & WHIPPLE, B. (1981) Female ejaculation: a case study. Journal of Sex Research, 17, pp. 13-21.
79. WEISBERG, M. (1981) A note on female ejaculation. Journal of Sex Research, 17, p. 90.

80. LADAS, A.K., WHIPPLE, B. & PERRY, J.D. (1982) The G-spot. New York, Rinehart and Winston.
81. DE BRUIJN, G. (1983) Ejaculatie bij vrouwen. Mensen, 6, p. 28.
82. ELLIS, H. (1937) Studies in the psychology of sex. New York, Random House, p.2.
83. VAN DE VELDE, T.H. (1924) Het Volkomen Huwelijk. Amsterdam, Querido.
84. MCGARY, J.L. (1973) Human Sexuality. New York, Van Nostrand Company.
85. GRAFENBERG, E. (1950) The role of the urethra in female orgasm. International Journal of Sexuology, 3, pp. 145-148.
86. BORS, E. & COMARR, A. (1960) Neurological disturbances of sexual function with special reference to 529 patients with spinal cord injury. Urology Survey, 10, pp. 191-222.
87. SEVELY, J. & BENNETT, J. (1978) Concerning Female Ejaculation and the Female Prostate. Journal of Sex Research, 14, pp. 1-20.
88. CARDOZO, L.D. (1988) Sex and the bladder. British Medical Journal, 296, pp. 587-588.
89. ZUCKERMAN, M. (1971) Physiological measures of sexual arousal in the human. Psychological Bulletin, 75, pp. 297-329.
90. HOON, P.W. (1979) The assessment of sexual arousal in women. Progress in Behavior Modification, 7, pp. 2-61.
91. ZUSSMAN, L., ZUSSMAN, S., SUNLEY, R. & BJORNSON, E. (1981) Sexual response after hysterectomy-oophorectomy: Recent studies and reconsiderations of psychogenesis. American Journal of Obstetrics and Gynecology, 140, pp. 725-729.
92. GEER, J.H. (1980) Measurement of genital arousal in human males and females, In: I. Martin & P.H. Venables (Eds.) Techniques in Psychophysiology. New York, Hariton and Singer.
93. KUHN, R.A. (1950) Functional capacity of the isolated human spinal cord. Brain, 73, pp. 1-51.
94. GRAY, D.J. (1973) Gray's Anatomy (35 edition). Longman.
95. DONKER, P.J. (1986) A study of the myelinated fibers in the branches of the pelvic plexus. Neurology and Urodynamics, 5, pp. 185-202.
96. GODEC, C.J. & BATES, H. (1984) Cholinergic receptors in corpora cavernosa. Urology, 24, pp. 31-33.
97. GU, J., POLAK, J.M., PROBERT, L., ISLAM, K.N., MARANGOS, P.J., MINA, S., ADRIAN, T.E., MCGREGOR, C.P., O'SHAUGHNESSY, D.J. & BLOOM, S.R. (1983) Peptidergic innervation of the human male genital tract. Journal of Urology, 130, pp. 386-391.
98. GU, P., POLAK, J.M., LAZARIDES, M., MORGAN, R., PRYOR, J.P., MARANGOS, P.J., BLANK MA, & BLOOM S.R. (1984) Decrease of vasoactive intestinal polypeptide (VIP) in the penises from impotent men. Lancet ii, 11, pp. 315-317.
99. LEVIN, R.M. & WEIN, A.J. (1980) Adrenergic alpha receptor outnumber beta receptors in human penile corpus cavernosum. Investigative Urology, 18, pp. 225-226.
100. VAALASTI, A., TAINIO, H., PELTO-HUIKKO, M. & HERRONEN, A. (1986) Light and electron microscope demonstration of VIP- and encephalin immunoreactive nerves in the human male genitourinary tract. Anatomical Record, 215, pp. 21-27.
101. OTTESEN B. (1983) Vasoactive intestinal polypeptide as a neurotransmitter in the female genital tract. American Journal of Obstetrics and Gynecology, 147, pp. 208-224.
102. OTTESEN, B., ULRICHSEN, H., FAHRENKRUG, J., LARSEN, J.J., WAGNER, G., SCHIERUG, L. & SØNDERGAARD, F. (1982) Vasoactive intestinal polypeptide and the female genital tract: Relation to reproductive phase and delivery. American Journal of Obstetrics and Gynaecology, 143, p. 414.

103. KRANTZ, K.E. (1958) Innervation of the Human Vulva and Vagina. Obstetrics and Gynaecology, 12, pp. 382-396.
104. OWMAN, C., ROSENGREN, A. & SJöBERG, N.O. (1967) Adrenergic innervation of the human female reproductive organs: a histochemical and chemical investigation. Obstetrics and Gynecology, 30, p. 763.
105. BURGOS, M.H. & DE VARGAS-LINARES, R.C.E. (1978) In the human vagina. E.S.E. Hafez & F.N. EVANS (Eds.) Amsterdam, North Holland Publishing Co, p. 63.
106. MINH, M.H., SMADJA, A., DE SIGALONY, J.P.H. & AETHERR, J.F. (1981) Role du Fascia de Halban dans la physiologie orgasmique feminine. Cahiers de Sexuologie Clinique, 7, pp. 169.
107. SCHRODER, H.D. (1985) Anatomical and pathoanatomical studies on the spinal efferent systems from birth to maturity. Journal of Urology, 48, pp. 759-777.
108. TWOMBLY, G. & LANDERS, D. (1956) The innervation of the bladder with reference to radical hysterectomy. American Journal of Obstetrics and Gynecology, 71, pp. 1291-1300.
109. MUNDY, A.R. (1982) An anatomical explanation for bladder dysfunction following rectal and uterine surgery. British Journal of Urology, 54, pp. 501-504.
110. ELBADAWI, A. & GOODMAN, D.C. (1980) Autonomic innervation of accessory male genital glands. In: Spring-Miller, E.S.E. Hafez (Ed.) Male accessory sex glands. Haarlem, Elsevier.
111. EHRHARDT, A.A. (1979) Psychosexual adjustment in adolescence in patients with congenital abnormalities of their sex organs. In: H.L. Vallet & I.H. Porter (Eds.) Genetic mechanisms of sexual development. New York, Academic Press.
112. PERCY, J.P., SWASH, M., NEILL, M.E. & PARKS, A.G. (1981) Electrophysiological study of motor nerve supply of pelvic floor. Lancet, I, pp. 16-17.
113. SPALTEHOLZ, W. (1929) "Handatlas des Anatomie des Menschen" Band III 786 Auflage 12. Leipzig, Hirzel.
114. MOULD, D.E. (1980) Neuromuscular aspects of women's orgasm. Journal of Sex Research, 16, pp. 193-202.
115. STOECKHART, R. (1985) Anatomische aspecten van seksuele processen bij man en vrouw. In: J.G. Van Dijk, et al. (Eds.) Libidoproblemen bij man en vrouw. Leiden, Boerhaavecursus.

Chapter 3

Physical and psychological implications of gynaecological cancer

3.1 Some basic information on cancer of the female genital tract[1-9]

3.1.1 Introduction

The aim of this chapter is not to give an extensive review of the research into female genital cancer and its treatment, but to provide a brief overview of the most common cancers of the female genital tract for a wide spectrum of workers in the field of gynaecological oncology, including e.g. social workers and psychologists.

Cancer is considered to be a malfunction of the cell in which the normal mechanisms of growth control are disturbed. This results in distinctive changes in the cell and aberrant tissue patterns. Cancer is not one disease, but several separate diseases, which can occur at any anatomic site, display specific biologic behaviour and responsiveness to treatment modalities and have multiple etiologies. In general, if these diseases are left untreated, they will, directly or indirectly, result in death.

Cancer of the breast is the most common type of cancer among females, followed by cancer of the colon, endometrium, cervix, lung, and ovary respectively. Female genital malignancies account for 14% of deaths due to cancer in the Netherlands.

The registration of patients with cancer is not compulsatory in this country. Therefore, no exact data on the incidence of malignancies in the Netherlands are available. The approximate incidence rates mentioned in this overview have been adopted from the "Stuurgroep Toekomstscenario's Gezondheidszorg: Kanker in Nederland".

3.1.2 Endometrial Cancer

3.1.2.1 Incidence

The incidence of endometrial cancer in 1985 was about 16.3 per 100,000 females. This means that in the Netherlands, about 1200 women will be found to be suffering from endometrial cancer and about 350 women will die from this disease per year.

3.1.2.2 Etiology

The various investigations on the etiology of endometrial cancer have consistently reported reproductive disturbances and endocrine function variables as risk indicators. Late menopause, nulliparity, obesity (diabetes mellitus), oestrogen replacement therapy and possibly hypertension are related to an increased risk of endometrial cancer.

3.1.2.3 Diagnosis

Endometrial cancer mainly occurs in postmenopausal women; the most common symptom is abnormal vaginal bleeding. The older the woman, the more likely it is

that the bleeding will be caused by cancer. Women who present with postmenopausal bleeding should undergo curettage to rule out invasive cancer. In the premenopausal patient, increased, prolonged, frequent or intermenstrual bleeding may be present. Pain is a late symptom and indicates a poor prognosis.

3.1.2.4 Tumor Spread

In general, endometrial tumor growth is slowly progressive and tumor spread occurs most commonly by direct invasion of the adjacent structures. Lymphatic spread is also encountered, mainly to the pelvic and para-aortic lymph nodes. Hematogenous spread is less common and results in metastases, particularly in the lungs and/or liver. Important factors for the prognosis and treatment of endometrial cancer are: the stage of the disease (Stage I, II, III or IV, determined by clinical evaluation), the histological grade of the disease (Grade 1, 2 or 3, well, moderately or poorly differentiated, respectively) and the depth of invasion. The higher the stage and grade of the disease and the deeper the invasion, the poorer the prognosis. Additional contributing factors to the prognosis are lymphatic spread and the presence of malignant cells in blood vessels and in fluid from the peritoneal cavity.

3.1.2.5 Treatment

Nationally and internationally, great plurality exists in the treatment of endometrial cancer. The primary treatment of choice is surgery, which may be combined with radiation therapy or sometimes adjuvant hormonal therapy or occasionally with chemotherapy.

A primary surgical approach allows the proper identification of risk factors. The operation may vary from a simple hysterectomy with removal of the tubes and ovaries in early stage disease to radical hysterectomy with pelvic and para-aortic lymphadenectomy in more advanced stages. A radical hysterectomy not only involves the excision of the uterus, the tubes and ovaries, but also the tissue between the uterus and pelvic wall, the proximal vagina and pelvic and some para-aortic lymph nodes.

The tubes and ovaries have to be removed irrespective of the stage of the disease because of a 5 to 10% chance of metastases.

Radiation therapy methods may also vary. Intracavitary (internal) or external radiation therapy, before and/or after surgery is performed to prevent recurrent disease in the vaginal vault and in the pelvic area.

Adjuvant hormonal treatment is given when the tumor cannot be treated satisfactorily by surgery and/or radiation therapy, if distant metastases are present and in case of recurrence of the disease. The likelihood that a tumor will respond to hormonal treatment is increased in patients with well-differentiated (Grade 1) tumors and in patients in whom a large time interval has elapsed between primary treatment and tumor recurrence.

3.1.2.6 Prognosis

The 5-year survival rate for Stage I disease varies from 90% for well-differentiated lesions not invading the myometrium, to 30% in the case of lymph node metastases. For Stage II disease,the 5 year survival rate is about 50%, for Stage III about 30% and for Stage IV 5%.

3.1.3 Cervical cancer

3.1.3.1 Incidence

In the Netherlands, the annual incidence of cervical cancer is estimated to be 10.2 per 100,000 females. In this country, about 2000 women will be found to be suffering from cervical carcinoma and about 300 women will die from this disease per year.

3.1.3.2 Etiology

Squamous cell carcinomas account for 80-85% of all invasive cervical cancers. About 10-20% of invasive cervical cancers are adenocarcinomas. The age group 45–60 years is at risk for cervical cancer but it may also be diagnosed in younger and older women. Risk indicators are the age at first coitus and the number of sexual partners; a venereal factor might also be involved, in this case the Human Papillomavirus (HPV) and smoking may be associated with squamous cell cervical cancer.

Carcinoma in situ (CIS) is a noninvasive cervical epithelial abnormality in which part of the outer layer of normal cells has been replaced by abnormal cells (disturbed maturation). The age-incidence curve for CIS has the same shape as the one for invasive cancer, except the peak occurs at an earlier stage. CIS has the same risk factors as squamous cell cervical cancer. Within 5-10 years, 25-50% of CIS will progress to invasive cancer.

3.1.3.3 Diagnosis

Some abnormal bleeding is experienced in approximately 80-90% of patients with invasive cervical carcinoma. It can take the form of postcoital bleeding, abnormal menstrual bleeding, intermenstrual or postmenopausal bleeding. In other women the only symptom may be vaginal discharge. Other symptoms, such as pelvic pain, swelling of the legs, urinary frequency and weight loss, are usually only seen in advanced stage disease. A minority of women are asymptomatic. Pelvic examination may reveal the lesion to be ulcerated or exophytic and it may bleed on palpation. Sometimes the cervix looks perfectly normal if the tumor is located in the cervical canal. Tissue has to be obtained to make an adequate diagnosis (colposcopy, curettage, biopsy, cone biopsy).

3.1.3.4 Tumor spread

There may be invasion of the disease into the vagina, pelvic wall, endometrium, bladder or rectum. Lymphatic spread mainly occurs to the pelvic lymph nodes and subsequently to the para-aortic lymph nodes. Hematogenous spread, particularly to the lungs, occurs in late stage disease.

3.1.3.5 Treatment

Very early stage disease (Stage Ia, depth of invasion less than 5 mm) may be treated by simple hysterectomy, or in special cases by cone biopsy. For more advanced disease a radical hysterectomy is indicated. A good alternative is radiation therapy, but this therapy does not allow proper identification of risk factors.

At the Groningen University Hospital, in stage Ib/IIa patients intracavitary radiation therapy is performed prior to surgery unless it is decided to preserve ovarian function in younger women with early stage disease and a small tumor volume.

Patients with lymph node metastases or inadequate surgical margins require additional external pelvic radiation. In more advanced disease radiotherapy is the treatment of choice. At the present time, chemotherapy for cervical cancer is still in the experimental phase.

Preinvasive cervical lesions can be treated effectively (i.e. 100% 5-year survival rate) by cone biopsy, cryocoagulation, colposcopically-directed excision-biopsy, cryosurgery, infrared coagulation and laser vaporisation.

3.1.3.6 Prognosis

The 5-year survival rate for Stage Ib disease varies from 85-90% in the absence of lymphatic metastases to about 55% in the presence of lymphatic metastases. For Stage IIA/IIB, the 5- year survival rate is about 60%, for Stage III about 30% and for Stage IV about 5%.

3.1.4 Ovarian cancer

3.1.4.1 Incidence

In the Netherlands the anual incidence of ovarian cancer is estimated to be 16.6 per 100,000 females. This means that about 1100 women will be found to be suffering from ovarian cancer and about 850 women will die from this disease per year.

3.1.4.2 Etiology

The age group 45-65 years is at risk for ovarian cancer although it can occur at all ages. The chance that a woman of over 40 will die from ovarian cancer is 1%.

Many histologically distinct neoplasms can originate in the ovary but most ovarian tumors are of the common epithelial type. The etiology of ovarian cancer is unknown. A reduced risk has been reported in women whose ovarian function has been suppressed for longer periods e.g. because of pregnancies, breast feeding, or the use of oral contraceptives. An increased risk has been observed in some families.

3.1.4.3 Diagnosis

Unfortunately, most patients who develop ovarian cancer are relatively asymptomatic until the disease disseminates. That is why ovarian cancer is sometimes referred to as a "silent lady killer". In early stage disease, the patient may complain of nonspecific symptoms, lower abdominal or pelvic "fullness", dyspareunia, irregular menses if she is premenopausal, or bleeding if she is postmenopausal. Symptoms from a mass compressing the bladder or rectum, such as urinary frequency or constipation, may induce the patient to visit a physician. Only rarely does a patient present with acute pain due to torsion or rupture of the tumor.

In advanced disease, which is present in 70% of the patients at the time of diagnosis, the most common complaints are abdominal pain, abdominal swelling, or vague gastrointestinal disturbances.

The swelling may be caused by the tumor itself or the associated ascites. Careful questioning usually reveals a history of vague abdominal symptoms, such as bloating, constipation, nausea, dyspepsia, anorexia, or early satiety.

3.1.4.4 Tumor Spread

Ovarian cancer typically spreads by cell dissemination forming implants throughout the peritoneal cavity, for instance, on the bowel, diaphragm and omentum. Generally, the cells grow around loops of intestine, encasing them with tumor, without invading the bowel lumen. The bowel obstruction caused by tumor growth is often incomplete and intermittent and may last for several months prior to the woman's demise. Death from ovarian cancer usually results from progressive encasement of the abdominal organs, leading to anorexia, vomiting and inanition.

3.1.4.5 Treatment

The primary treatment is surgery in order to remove the ovaries, tubes, uterus and omentum and to perform thorough surgical staging to rule out disseminated disease in the pelvic and para-aortic lymph nodes. Sometimes, in younger women with early Stage disease, one ovary is left in situ. In more than 50% of the cases it is not possible to remove all macroscopic disease. Under these circumstances an attempt is made to reduce individual tumor nodules to 1.5 cm diameter or less ("debulking"). Women in whom optimal debulking has been achieved prior to chemotherapy have longer median survivals and more frequently complete responses to therapy. It is still unclear whether this is the result of the surgery or of the chemotherapy or of the specific biologic behaviour of the tumor. Debulking may also be performed secondary to chemotherapy.

In patients who are clinically free from disease after completing a course of chemotherapy and for whom alternative treatment modalities are available, a "second look" laparotomy/laparoscopy can be performed to determine whether or not there has been a complete response to chemotherapy. If there is neither macroscopic nor microscopic evidence of disease, cessation of chemotherapy can be considered.

The effect of chemotherapy depends on the stage of the disease, the residual tumor volume after surgery, the histological type of the tumor, the histological grade of the disease and the general physical and mental condition of the patient. Combination chemotherapy regimes have resulted in a greater degree of response than was previously achieved with single alkylating agent therapy. Single alkylating agent therapy is still commonly used for frail or elderly patients.

Epithelial tumors are susceptible to radiation therapy. The application of external radiation enables a uniform dose to be delivered to a given field. The tolerance of normal tissue (bowel, bladder, liver, kidneys) limits the total dose that can be delivered. Therefore external radiation is mainly applied in cases without macroscopic residual tumor following surgery for early stage disease.

3.1.4.6 Prognosis

The 5-year survival rate of early stage ovarian cancer is about 76%. However, the overall 5-year survival rate of ovarian cancer is only about 45%.

3.1.5 Vulvar cancer

3.1.5.1 Incidence

Cancer of the vulva is the fourth most common female genital malignancy, accounting for approximately 5-8% of all gynaecological cancers. The percentage of women with cancer of the vulva is increasing, probably because people are reaching a more advanced age. In the Netherlands, about 140 women will be found to be suffering from vulvar cancer per year. Two thirds of these women will be older than 60 years; the average age at diagnosis is 65 years. However, cancer of the vulva can also occur in women of under 30.

Squamous cell carcinoma accounts for about 90% of vulvar cancer.

3.1.5.2 Etiology

No specific etiologic agent is known. A venereal factor might contribute to the pathogenesis (lues, herpes II and HPV) and the presence of chronic vulvar diseases might be more than coincidental.

3.1.5.3 Diagnosis

Vulvar cancer is well-known for its doctors' and patients' delay. Patients generally present with a vulvar lump. The lesion may be raised, ulcerated, pigmented, or warty in appearance and a definitive diagnosis must be made by biopsy. Most lesions occur on the labia majora; the labia minora are the next most common site. Less common sites include the clitoris and the perineum. Approximately 5% of cases are multifocal. Of these patients, 15% are suffering from or have suffered from a malignancy of the cervix (carcinoma in situ or invasive carcinoma) as well.

3.1.5.4 Tumor spread

Vulvar cancer spreads primarily by lymphatic routes. In most cases, the initial lymphatic metastases occur in the inguinal lymph nodes. From these nodes, spread occurs to the femoral nodes and later to the pelvic nodes. The incidence of lymph node metastases in vulvar cancer is approximately 30% and is related to lesion size/depth.

Approximately 5% of patients have metastases in the pelvic lymph nodes. Vulvar cancer spreads by direct invasion to adjacent structures, such as the vagina, urethra and anus. Hematogenous spread to distant sites, including the lungs, liver and bone, usually occurs in advanced stage disease and is usually preceded by lymphatic metastases.

3.1.5.5 Treatment

The primary treatment of vulvar cancer is surgery. The operation involves removal of the entire vulva from the perineal body to the upper margin of the mons pubis, including the lymph nodes and fatty tissue. The distal portions of the urethra and vaginal wall sometimes have to be removed in this en bloc dissection to obtain adequate surgical margins. If postoperative histological examination reveals tumor cells in the surgical margins and lymph node(s), adjuvant radiation therapy is given and sometimes chemotherapy (bleomycine).

3.1.5.6 Prognosis

The 5 year survival rate in the absence of lymphatic metastasis is 85-90% and in the presence of lymphatic metastasis 25-60%. Life-long medical control is required because these women are disposed to re-occurrence of vulvar carcinoma.

3.1.6 Rehabilitation

The treatment of gynaecological cancer is far from ideal. Treatment means that the diseased organ and the surrounding tissues are removed and destroyed, the surrounding healthy organs are often injured and the anatomy of the lower pelvic region is altered. In this way the woman with gynaecological cancer has been stripped and invaded, physically and psychologically.

It is estimated that in the coming years, more women will be faced with this devastating disease, mainly because of the ageing of the population. In the year 2000 more than 100.000 women will be alive with a diagnosis of cancer of the uterus, ovary or breast. This impels us, the workers in the field of gynaecological cancer today who are not only concerned with curative or successful palliative treatment of gynaecological cancer, to focus on rehabilitation more than ever.

3.2 Physical implications of gynaecological cancer*

3.2.1 Introduction

In this chapter sexual dysfunctions in gynaecological patients are discussed with emphasis on the physiological/ anatomical aspects. Firstly, sexual dysfunctions are described. Secondly, the impact of non-oncological hysterectomy and ovarian failure are discussed. Thirdly, the attention focuses on sexual functioning in gynaecological cancer patients 1) prior to the discovery of gynaecological malignant disease, 2) at the time of diagnosis and subsequent treatment and 3) after different treatment modalities for gynaecological malignant disease, i.e. surgery, radiation therapy and chemotherapy.

3.2.2 Sexual dysfunctions

The classification of sexual dysfunctions in the female is based on the Female Sexual Response Cycle. The five major manifestations of sexual dysfunction in the female are:[10]

1. inhibited sexual desire, 2. inhibited sexual arousal, 3. orgasmic dysfunction, 4. dyspareunia and 5. problems with resolution of sexual arousal.

Ad 1) Inhibited sexual desire; the term "inhibited sexual desire" characterizes those individuals who report that they are generally uninterested in sexual activity. The

* W.C.M. Weijmar Schultz, H.B.M. van de Wiel, J. Bouma & R.E. Lappöhn (1990) Gynaecological conditions and sexual dysfunction. Accepted by Sexual and Marital Therapy.

underlying idea is that every human being is basically motivated for sex. However, this is still a subject of much debate. Inhibited sexual desire can manifest itself behaviourally by avoidance of sexual contexts or refusal of sexual activity. Women with inhibited sexual desire report an absence or a low frequency of sexual phantasy or other pleasant, arousing cognitions. Emotionally, women with low sexual desire describe themselves as not feeling "sexy" and not being interested in initiating or responding to sexual activity.

Ad 2) Inhibited sexual arousal; sexual dysfunction during the arousal phase leads to inhibition or disruption of the predominant physiological responses, i.e. insufficient vaginal engorgement and/or lubrication makes penetration difficult. Dyspareunia may occur. Psychologically, the woman may report that she does not feel aroused and/or her body is not responding. As is also the case with desire-phase difficulties, subsequent orgasmic disruption can easily occur due to lowered levels of excitement.

Ad 3) Orgasmic dysfunction; when related to disease, the complaint more commonly comprises a dramatic decline in orgasm frequency or complete failure to achieve orgasm. These circumstances are typically accompanied by excitement difficulties as well: the woman feels that she does not even become sufficiently aroused to get close to experiencing an orgasm.

Ad 4) Dyspareunia; difficult or painful intercourse. It includes many variations, from vaginal discomfort or irritation after intercourse to extreme pain with penile thrusting.

Ad 5) Problems with resolution of sexual arousal; sexual dysfunction occurring specifically during the resolution phase has not been noted. However, women with excitement or orgasmic dysfunctions typically report discontentment with the resolution period as well as symptoms of continued vasocongestion, residual sexual tension, lack of satisfaction and negative impact. Those who experience pain during intercourse often suffer from residual discomfort immediately afterwards. Those without pain, per se, but lowered desire, arousal and/or orgasmic disruption, may have feelings of residual sexual tension, disappointment and/or concern that their sexual responsiveness has changed permanently.

3.2.3 Sexual functioning and non-oncological hysterectomy

While studying the literature on sexual functioning after hysterectomy for benign disease, it appears to be widely accepted that a simple hysterectomy has no biological effects on sexuality.[11-20] Bancroft, in his textbook "Human Sexuality and its Problems", stated that "there are no mechanical or physiological reasons why hysterectomy per se should impair sexual response" and "adverse sexual reactions may occur for psychological reasons".[21] In accordance with this assumption, most of the investigators of sexual functioning after hysterectomy explain or infer that changes in sexual functioning are primarily psychogenic. So far, these investigations

have failed to produce a consistent pattern of changes in sexual functioning after hysterectomy.[22]

Recent knowledge on the physiology of female sexuality suggests the possibility that sexual response following genital surgery may be at least partially determined by physiological variables as well.[23,24] For example, hysterectomy may change the sexual sensations of women in whom the uterus played an active role in their sexual response. During sexual arousal there may be less vasocongestive change in the pelvis due to the absence of the uterus, there will be no elevation of the uterus with sexual excitement and often no ballooning of the vagina with sexual arousal. The "tenting effect" may be limited by the inelasticity of the vaginal scar or the effect may be felt less because of sensory loss. The absence of the uterus could be noticed during the plateau phase as well, during which the extra increment of sexual tension might not be felt by a woman who has had a hysterectomy. Finally, some women experience orgasms that are purely uterine.[25,26] These women, after hysterectomy, will be very likely to regret having lost these uterine contractions.[27,28] For women who experience vulvar orgasms in particular, the loss of internal structures may not have a comparable effect. The surgical scar in the vaginal vault might make intercourse uncomfortable if the scarred area is struck by the penis during intercourse, although it is known that in most cases cautious return to intercourse will gradually stretch the vaginal tissues.[29] A simple hysterectomy does not cause shortening of the vagina, or only shortens it slightly and rarely causes dyspareunia.[30-32]

In contrast to a radical hysterectomy, during simple hysterectomy the risk of damage to the pelvic plexus is slight, because these nerves are situated well to the posterior and the bulk of the plexus lies below the cardinal ligament.

Kilkku[33] reported on the sexual functioning of women who were treated with conization for cervical dysplasia and CIS. After conization in which the uterine cervix was removed and most of the uterus was left in situ, he did not find any change in libido, experience of orgasm, coital frequency or overall sexual satisfaction. A significant decrease in the number of women with dysmenorrhoea and dyspareunia became manifest and was explained by Kilkku as a possible result of the removal of the diseased cervix ("cervicitis"). From this study it appears that the removal of the cervix does not disturb the female sexual response.

Kilkku and colleagues also studied the sexual functioning of women before and after simple abdominal hysterectomy and before and after "supravaginal hysterectomy".[32,34] During a supravaginal hysterectomy, most of the uterus was removed while the cervix was left in situ. This means that there was no destruction of the normal form of the vaginal cuff and no formation of scar tissue in the cuff. Consequently, a great deal of support from the surrounding tissue was maintained and no loss of the "tenting effect" occurred during arousal. No statistically significant changes in sexual function could be detected either between the two groups or within the separate groups, with the exception of orgasmic frequency. In the hysterectomy group, a highly significant reduction in orgasmic frequency became manifest while in the supravaginal hysterectomy group this reduction in orgasmic frequency did not occur. The greater frequency of dyspareunia after total hysterectomy only partly explained the difference and dyspareunia may be the effect of diminished arousal as well.

In his articles, the author stressed the fact that he himself interviewed and examined the women each time, thus "making the results more reliable". We think that this technique has the opposite effect and that psychometrically reliable and valid scales might have provided more reliable results. Nevertheless, if these observations can be confirmed by others, they will stress the importance of the tissues surrounding the uterus, i.e. the vaginal cuff, the parametrium and the paracolpium, for orgasmic capacity, unless the loss of orgasmic capacity is related to subconscious psychological reactions.[35] It is possible that hysterectomy patients experience the total removal of the uterus as a greater loss than supravaginal hysterectomy patients do, because they still retain part of the uterus. Further research may be directed at examining organic factors and psychological factors as possible determinants of the sexual response after hysterectomy.

Removal of the uterus by the vaginal route carries no extra risk of disruption of the sexual response. The faster recovery and the absence of an abdominal wound will promote the resumption of sexual activities. Besides, the women who are usually eligible for this vaginal approach are middle-aged and will have given birth to children. For them, the operation may mean the fulfillment of a longstanding wish to bid farewell to contraception.

3.2.4 Sexual functioning and ovarian failure

Hot flushes, insomnia, fatigue, mood lability, headaches, paresthesia and skin-crawling sensations may characterize ovarian failure.[36] In addition to these symptoms, each of which may affect sexual functioning, physiological changes in the sexual response cycle may occur. These changes include reduced and delayed production of vaginal lubrication, thinning and atrophy of the vaginal epithelium, reduced involuntary expansion of the vagina and diminished orgasmic response.[37] Further deterioration of these symptoms may be expected after surgery, chemotherapy and radiation therapy and from reduced sexual activity.[38] Dyspareunia often occurs. Epidemiological studies on the effect of depletion of oestrogen and progesterone at the menopause suggest an associated decline in female sexual interest, capacity for orgasm and coital frequency.[39,40] In a study on oestrogen replacement therapy following oophorectomy, it has been reported that these hormones produce an enhancement effect on sexual desire, enjoyment and orgasmic frequency.[41] On the one hand, this might be due to an improvement in the general condition because of the oestrogens. On the other hand, oestrogen therapy will induce proliferation of the vaginal epithelium, resulting in relief of symptoms of atrophic vaginitis and frictional dyspareunia. It can be administered either systemically or directly to the vagina as a cream.[42]

There is strong evidence that in low oestrogen situations, androgens may also promote growth of the vaginal epithelium.[38,43] A prospective, cross-over study has shown that women who received a combined oestrogen-androgen drug after surgical menopause had higher energy-level and well-being scores and lower psychological-symptom scores than patients who received oestrogen alone or placebo postoperatively.[44] Women who received both sex steroids also reported an increase in the cognitive aspects of sexuality, such as desire, arousal and the number of sexual fanta-

sies.[45] The finding that androgens enhance sexuality was supported by the results of a study in which matched groups of surgically menopausal women on long-term treatment with either an oestrogen-androgen combined drug or with oestrogen alone, were compared.[46] These androgenic effects have also been corroborated by other investigators who used subcutaneous implants of pellets containing oestradiol plus testosterone or oestradiol alone.[47,48]

These are very important observations because during the past two decades, it has been established that both premenopausal and postmenopausal ovaries produce a significant quantity of androgens. In women of reproductive age, the ovaries produce approximately one-third of the total quantity of circulating androgens, including 25% of the total plasma testosterone, which is the most potent aromatizable androgen with central nervous system actions. In approximately 50% of women, the ovarian stroma continues to produce androgens for some time after the menopause, while in the other half, postmenopausal ovarian androgen production is significantly reduced or entirely halted.[49] Surgically-menopausal women are, of course, deprived of ovarian androgens as a consequence of bilateral oophorectomy and their circulating levels of testosterone decrease significantly within the first few days after surgery.[50]

This means that it is important to dismiss the concept that the postmenopausal ovary is a senescent or dead structure and to recognize the fact that in many women hormone production in the postmenopausal ovary is maintained for many years after the onset of menopause. In contrast to spontaneous ovarian failure, cessation of function due to oophorectomy and possibly to irradiation and chemotherapy as well, means a sudden drop not only in the oestrogen but also in the androgen supply. Therefore, it can be expected that iatrogenic ovarian failure will have a greater impact on female sexual functioning than spontaneous ovarian failure. Prospective research on this issue is lacking.

3.2.5 Sexual functioning and gynaecological malignant disease

3.2.5.1 Sexual functioning immediately prior to the discovery of gynaecological malignant disease

Prior to the discovery of gynaecological malignant disease, signs such as fatigue, postcoital bleeding, vaginal discharge and pain, may alert a woman to her gynaecological disease and the need for medical care. These symptoms constitute sexually disruptive effects and may also cause sexual dysfunctions. Until recently, the sexually disruptive effects of these early signs and symptoms had not been studied. In a longitudinal investigation on forty-one women recently diagnosed with early stage cervical or endometrial cancer, Andersen et al.[10] found substantial damage to sexual functioning in 75% of these women prior to diagnosis and treatment. Before the appearance of symptomatic disease, these women reported patterns of sexual activity and responsiveness that were similar to those in a matched healthy sample. Sexual problems included inhibited sexual desire (56%), inhibited sexual arousal (49%), inhibited orgasm (37%) and dyspareunia (37%).

3.2.5.2 Sexual functioning at the time of diagnosis and during the subsequent treatment of gynaecological malignant disease

The diagnosis of cancer and the nature of cancer therapy may evoke anger, frustration, fear, sadness and resentment. In a situation with such emotional states, a woman and her partner may have little interest in sharing sexual intimacy. Many cancer patients experience significant physical debilitation during treatment or even after complete recovery. Fatigue specific to surgery,[51] chemotherapy,[52] and radiotherapy[53] has been described. In addition, signs and/or symptoms of other illness may be present. Patients requiring radical surgery may continue to report significant debilitation, such that social and sexual activities are severely restricted. These limitations could produce desire problems or reduced arousal or orgasm potential, even when there is sufficient desire for sexual activity.[54]

3.2.5.3 Sexual functioning after treatment for gynaecological malignant disease

3.2.5.3.1 Sexual functioning and radical hysterectomy Radical hysterectomy is a major operation, involving considerable morbidity and necessitating a long period of physical and mental rehabilitation. During radical hysterectomy, not only the uterus, the tubes and the ovaries are removed, but also the tissue between the uterus and the pelvic wall, the proximal vagina and the pelvic lymph nodes. The physiological problems associated with the loss of sexual organs and altered anatomical structures have already been mentioned. Removal of the upper part of the vagina during radical hysterectomy compounds these physiological problems mainly because the field of excision is likely to involve the pelvic plexus.[56-60] However, complete autonomic denervation by surgery is unlikely because autonomic nerves, after having entered the pelvic plexus, are widely dispersed over the side walls of the pelvis.[55,61] Studies on the neurophysiological function of the genito-urinary tract after radical hysterectomy, dealing with bladder function, did reveal partial parasympathetic denervation[62-65] and indicated damage to sympathetic nerves as well.[56,58] All these studies agree that sensory loss occurs. It is generally accepted that the degree of urinary dysfunction is dependent on the radicality of the operation, with special emphasis on the length of the vaginal cuff removed[56,58,62,67-69] and on the extent of lateral dissection.[69] Changes in bladder function are usually a temporary effect of the operation but may in some cases persist for the rest of the patient's life. Because both genital and urinary neurophysiological function are closely intertwined, disruption of autonomic and sensory nerve supply to the vagina and surrounding vessels is obvious. More specifically, damage to the nerves will be detrimental to vaginal vasocongestion, lubrication, expansion and sensory perception during arousal and coitus.

It has been reported that loss of physiological cortical sensory input from the bladder can be substituted by less sensitive indicators: sensations of bloating and vague pelvic heaviness during vesical distention have been mentioned, probably due to peritoneal stretching and pressure on the adjacent abdominal viscera.[56,62,66,70] It might be possible that the loss of sexual sensory input may be substituted by other less sensitive indicators as well.

The removal of the vaginal cuff will shorten the vagina. The trigonum of the bladder as well as the sigmoid colon may be densely adherent to the new vaginal apex.

Penile thrusting can, therefore, be painful and interfere with sexual arousal.[71,72]

The role of pelvic surgery in reducing the blood circulation to the vagina, or indeed in affecting vaginal lubrication by any mechanism, is not clear.

Urinary dysfunction can also interfere with sexual functioning. Abnormalities include obstructive voiding patterns, immediate and delayed loss of compliance, sensory loss and genuine stress incontinence. The frequency of severe urinary disability is estimated to be at least 5%.[69]

It is unknown to what extent pelvic lymph node dissection during radical hysterectomy contributes to sexual dysfunction afterwards. Because lymphatic vessels and nerves are intimately interwoven and cannot be distinguished during surgery, damage to the nervous system seems unavoidable. As long as the functional details of the autonomic nervous system for the sexual response in the female under normal circumstances have not been clarified, evaluation of the impact of pelvic lymph node dissection on the female sexual response will be impossible.

3.2.5.3.2 Sexual functioning and radical vulvectomy Radical vulvectomy ranks with mastectomy in its impact on the psychological make-up of a woman and her sexual response. This consideration is particularly relevant in an era in which reports seem to indicate that premalignant and early invasive neoplasia of the vulva are occurring with increasing frequency in young age groups.[73-75] The postoperative physical consequences, involving scars, stenosis of the vaginal introitus and lymph oedema of the lower limbs, can be very troublesome.

The urethral opening becomes exposed, leading to local swelling and tenderness (caruncula urethrae). Sometimes shortening of the urethra, caused by surgery, gives rise to urinary tract infections, especially after sexual activity. Due to scarring, the urinary stream may be skewed laterally. Occasionally the urethra may be drawn beneath the pubic arch or "hooded" so that it empties into the lower vagina. Cystocele may easily become manifest because of loss of supporting tissue. Stress incontinence may arise. The odour of urine as well as recurrent bladder infections under these conditions act as barriers against physical intimacy.

Healing of the wound induces extensive scarring with long-term numbness and/or paresthesia. There is no tissue mobility and no cushion over the pubis for the "male-superior" position. All too often, the final vaginal aperture is a small opening surrounded by displaced pubic hairs. Penile intrusion may not be felt. Sometimes introital adequacy has to be created by additional surgery. Nerve regeneration has been known to occur.[76] Foreplay, an important sensual ingredient, is adversely affected in women who have undergone radical vulvectomy because of impairment of the sensory nerve perceptors in the labia, clitoris and lower vagina.

Damage to the pudendal nerve is limited to the peripheral nerve endings with concurrent loss of sensitivity. The pudendal nerve supply to the pelvic floor muscles, the site of the response which is thought to be the essence of the female orgasm,[37] is not blocked. Orgasmic failure is assumed to be mainly due to interference with a woman's awareness of genital sensations and to interference with central arousal: therefore, age, motivation and existing patterns of coital activity may be just as important as the extent of surgery.

3.2.5.3.3 Sexual functioning and major nerve damage Damage to the femoral nerve, the sciatic nerve, the obturator nerve, the genitofemoral nerve, the ilioinguinal and hypogastric nerves and the lateral femoral cutaneous nerve has been specifically associated with radical pelvic surgery, but appears to be infrequent: 1.06%.[77] Results of injury to these major nerves include impaired muscular functioning of the lower extremities (femoral, sciatic and obturator nerve), numbness or sensory loss over the medial thigh (obturator nerve), numbness or paresthesia of the labia and skin covering the femoral triangle (genitofemoral nerve) and numbness or paresthesia over the suprapubic region, the upper medial thigh and the anterior part of the labium majus (ilioinguinal and iliohypogastric nerves).

Full recovery of impaired muscle function and sensitivity has been observed within a few months, depending on the degree of injury. Of course, such complications interfere negatively with rehabilitation after gynaecological cancer treatment, but are regarded as being of minor importance for sexual rehabilitation in particular.

3.2.5.3.4 Sexual functioning and radiation therapy Many patients experience significant physical debilitation during and shortly after radiation therapy, which leads to a reduction in interest in sharing physical intimacy in this period.[53] Later on, the radiation-therapy-induced late complications constitute the major disturbing effect on the sexual response.

Radiation therapy in patients with carcinoma of the cervix may cause damage to skin, subcutaneous tissue, the bowel especially the rectum, the urinary bladder and the ureters.[78-80] Complications resulting from preoperative caesium treatment or postoperative external irradiation occur infrequently and the symptoms are usually mild and temporary. Severe complications requiring surgical intervention have been observed in 1-2% of the cases.[79,80]

In patients treated exclusively by radiotherapy, complications occur far more frequently (up to 17%), in particular in the distal part of the digestive tract.[79] Many patients experience diarrhoea and cramp. Complications in the rectum (tenesmus, haemorrhage, pain) do not usually begin until 6-12 months after radiation. Injuries to the bladder (necrosis, haemorrhage) and ureter (hydroureter) seldom occur but may appear many years after primary treatment.

The function of the vagina is not comparable to the urinary bladder or rectum and, therefore, has been disregarded more frequently during the application of therapeutic measures for cancer. In fact, radiotherapy interferes to a much greater extent with vaginal function than radical surgery does. An irradiated organ never really recovers.[71] Ionizing radiation has a direct effect on the basal layer of the vaginal epithelium, which is highly radiosensitive, on the endothelium of the small vessels and on the fibroblasts of the connective tissue in the subepithelium which are moderately sensitive.[81]

Due to narrowing and obliteration of the small vessels and the increase in fibrosis, the vascular system's ability to dilate is restricted, thus inhibiting vasocongestion/lubrication and the sensory nerve responses integral to arousal and achievement of orgasm. Anatomical distortions within the vaginal canal due to radiation therapy, e.g., loss of elasticity of the vaginal canal and fibrosis, may impair physiological

responses to sexual stimulation by limiting the phenomena of lengthening and expansion of the vagina during sexual activity.[82]
Dyspareunia may arise because of

- thinning of the epithelium with diminution of natural lubrication,
- increased predisposition to trauma and infection,
- reduced frequency of sexual activity and
- age-related and ovarian-failure-related diminished vitality of the tissues leading to atrophy, hypoplasia and tissue break-down of the vaginal epithelium.

These sequelae of radiation therapy also contribute to pain or discomfort on pelvic examination. More than 80% of the women have some degree of acquired vaginal stenosis following therapeutic irradiation,[71,84] in particular stricture of the upper third of the vagina. Complete vaginal occlusion occurs less frequently. Sexual disruption is most severe in women treated with radiotherapy alone[71] and in women with very infrequent coital activity.[84] The modest vaginal changes in patients treated with a combination of radiation and surgery is due to the much lower total dose of radiation received compared to the patients who are treated with radiation only. Moreover, in the former patients the upper 1/3 of the vagina, which is normally exposed to the largest dose of radiation, has been removed during the operation.

The use of a vaginal dilator or vaseline tampons and early coital resumption are mentioned in the literature as preventive measures to stave off vaginal adhesions and diminished patency.[85-87] It has been estimated that radiation-induced tissue changes may continue for 36 months after the completion of therapy.

All women who receive abdominal or pelvic irradiation develop irreversible ovarian failure, if the ovaries have not already been removed during the preceding surgery, or transferred out of the radiation field beforehand. The benefit of this transposition is still a controversial subject.[88,89]

Adjuvans radiation therapy after radical vulvectomy, because of cancer of the vulva, may cause extra damage to the skin and subcutaneous tissue and aggravate the physical consequences of the treatment.

3.2.5.3.5 Sexual functioning and chemotherapy Poor physical condition during chemotherapy precipitates at least a temporary cessation of sexual activity. After chemotherapy, ovarian failure constitutes the major disturbing effect on sexual reponse: hormonal replacement therapy has been observed to dramaticly relieve disturbing symptoms, such as a dry vagina, painful intercourse and decreased libido.[90,91] The positive impact of hormonal intervention on the sexual response in these patients might be tempered if the disturbing effects of surgery, which frequently precede chemotherapy, prevail.

Theoretically, if polyneuropathy arises, this might disturb the sexual response as well. Peripheral neuropathy has been known to occur particularly in the hands and feet of some patients treated with CIS platinum and/or Vinblastine.[92,93]

Hair loss due to chemotherapy can take up to six months to recover and is a constant reminder of the altered body-image brought about by cancer. These individuals

see themselves as less attractive to others, they have a poor self-image and are likely to either avoid sexual activity or not enjoy the experience.[94]

3.2.5.4 Summary

The mechanisms underlying the female sexual response may be impaired by surgery, pelvic or vaginal irradiation and chemotherapy or indirectly by ovarian failure. These treatment modalities cause vaginal stenosis, atrophy and irritation of the mucosa and inadequate lubrication, which often results in painful intercourse. The depth and caliber of the vagina itself may be altered. A change in cortical sensory input may occur.

Somatization effects are related to the disruptive effects of physical debilitation, or are the result of the cancer patient focussing on body sensations.[95] In this way she becomes a "spectator" rather than a "participant" during love-making or becomes unduly aware of how she and her partner are responding, which often results in sexual dysfunction, particularly orgasmic difficulties.[96]

In addition, cancer patients may need to distantiate themselves from other unpleasant body sensations, such as pain[97] if their arousal is to proceed without impairment. Also, priorities in life may be altered.[54] For example, the knowledge that one has a life-threatening disease may precipitate the cessation of all sexual activity.

Western culture's idealization of youthful beauty, blatantly reminds women that a perfect body is required for physical attractiveness and sexual desirability. This value orientation can lead to diminished self-esteem for all who suffer from a discrepancy between the ideal and actual body-image.[98,99] Cultural pressure on those who perceive a loss of physical female identity, compounds irrevocable physiological problems of altered anatomical structure and loss of sexual and reproductive organs. Frequently it is hardly possible to distinguish between the physiological/anatomical and psychosocial sources of sexual dysfunction. Therefore, we need to be cautious in attributing a psychogenic cause to a disorder, when organicity is possible and vice versa.

3.3 Psychological implications of gynaecological cancer treatment

Most people envision cancer as a uniquely frightening illness. Cancer is associated with progressive physical debilitation, passive submission to protracted treatment that may involve pain, mutilation and a capricious course that creates a pervasive sense of uncertainty.[100]

Although everybody is aware of the relatively large scale existence of cancer, nobody really expects to become a cancer patient: "It only happens to others". This phenomenon is not unique for cancer; more or less the same ideas exist with regard to traffic accidents, natural disasters, being robbed or victimised and many other forms of threatening events. This "ignorance" stems from a very central idea of invulnerability, which is a very basic and functional assumption that enables us to pay attention to more relevant situational cues. Daily activities would become impossible if one had to worry about all kinds of things that could happen. Therefore these

kinds of interfering thoughts are overruled by the general idea of "invulnerability". Confrontation with an unexpected negative event with far reaching implications which undermines this assumption, will be experienced as shocking. In the case of becoming a cancer patient, this shock is so tremendous that one could speak of a (psycho)trauma.

If one thing has become clear from studies on the consequences of shocking experiences, it is the huge variety of ways in which people react to a traumatic event. This variety of reactions seems to be very much in contrast with the similarity and uniformity of the adaptation process itself.[101]

Because of this uniformity, we would like to take the process of adaptation as a starting-point for our discussion on the psychological consequences of gynaecological cancer treatment. After discussing the process of adaptation, determinant factors of adaptation will be discussed.

3.3.1 The process of adaptation

In our description of the process of adaptation we will make use of the work by Kleber et al.,[101] who developed an integrative model of adaptation. Although this model is a combination of psychodynamic points of view, parts of stress-theories and other theories, it can be best classified as a cognitive model.

3.3.1.1 Cognitions

Cognitions may be thoughts, expentancies, attitudes, opinions, or even perceptions, in fact all mental processes in which sensory input is transformed, reduced, catagorized and analyzed in terms of meaning for the individual. Cognitive psychology is rapidly gaining influence in present day psychological research and has therefore been chosen as the overall theoretical orientation in this study. Cognitive psychology itself is based on an interactionistic model which will be discussed here briefly first.

A basic element in the interactionalistic model for human behaviour is the focus on the ongoing, multidirectional interaction between an individual and his or her environment, especially a situation in which behaviour occurs.

Persons and situations are regarded as indispensably linked to one another during the process of interaction. Behaviour is determined by inseparable person-situation interactions. This view has the consequence that research has to focus simultaneously on person factors, situation factors and the interaction between these two systems. According to Magnussen and Endler[102] the basic elements of the interaction model can be summarized as follows:

- actual behaviour is a function of a continuous process of multidirectional interaction or feedback between the individual and the situations he or she encounters;
- the individual is an intentional, active agent in this interaction process;
- on the person-side of the interaction, cognitive and motivational factors are essential determinants of behaviour;
- on the situation-side, the psychological meaning of situations for the individual is the major determining factor.

Cognitions play an important role in this theory because they can be seen as the intermediators between the person and the situation.

According to Kleber et al., integration of a shocking event into daily life requires a general psychological process which Horowitch[103] calls "the stress response syndrome". This process starts in response to a shocking experience (also called a (psychotrauma), which can be defined as a situation characterized psychologically by:

a) extreme powerlessness and helplessness
b) acute disruption of basic assumptions and beliefs
c) extreme distress.

Cancer patients meet these criteria because they see themselves confronted with a severe, irreversable, negative situation. This makes them feel helpless, powerless and sometimes useless. As cancer is a life-threatening disease and a cure is not guaranteed, it destroys the patients certainty about the future and demands revision of fundamental ideas and expectations. Becoming a cancer patient means confrontation with ones own barriers, ones vulnerabiliy and the risk of dying; it brings about an existential crisis.

3.3.1.2 Regaining control

After treatment the existential crisis ends but this does not mean that the individual who has been treated for cancer is able to continue his life as if nothing has happened. Integration of this life event and its consequences is needed, which asks for a new conceptual framework of meanings. The rebuilding of this framework can be seen as a process in which the events of becoming a cancer patient, i.e. being treated for cancer and all the implications, have to be integrated into already existing ideas, expectancies and meanings (cognitions). As long as this integration has not been established, the discrepancy will be displayed in the form of emotional disturbances, such as fear of recurrence, feelings of guilt, depression or anger.

This process of adaptation can be seen as a way of regaining control over the new situation. Within this process, time plays an important role. Kleber et al. distinguished two phases. The process starts as soon as an individual is confronted with a traumatic event. Some people react with intense emotional reactions but most seem to hardly react at all, they are benumbed. This first phase usually does not last very long and is followed by the second and most characteristic phase of adaptation.

This second phase can be observed as a reaction to virtually all types of trauma, irrespective of the background. It therefore can be considered as the central concept of the stress-response syndrome. Typical is the continuous alternation between denial and intrusion. Denial is manifested in the avoidance of event-related activities, e.g. the refusal to think about the event, emotional numbing, and so on. Intrusion refers to re-enactments of the event, intrusive thoughts and feelings, nightmares, preoccupation, and so on.

The alternation between the two processes is involuntary but always meaningful. Denial provides time and energy to recuperate and prevents the person from being overwhelmed by emotions. Intrusion facilitates the awareness of the event and its implications. New assumptions, meanings and expectations can be developed on the

basis of this repetitive scanning of the experience. In the oscillation between intrusion and denial, the person regains control over his life.

Both processes can be seen as complementary parts of the adaptation process. When one of the two processes becomes dominant, or when both occur to an extreme extent, the individual adjustment will be inhibited. During the phase of adaptation, strong emotional disturbances take place due to the adjustment of expectancies and assumptions. These emotional reactions are not only the result of the adjustment procedure, but also serve as guide-lines for the process itself.

The process ends when integration of the traumatic event has been fully reached and the oscillation between denial and intrusion is no longer involuntary but under the control of the person him/herself. The person is no longer preoccupied by the event and is no longer overwhelmed by it. The process of coping with such experiences takes energy and time. It involves considerable distress and "pain" for people to achieve full awareness of the consequences of the shock. This process of coping with the dreaded disease and its sometimes even more frightening treatment, starts at the moment of initial diagnosis and does not end with tumour removal or dicharge from hospital. On the contrary, when the patient goes home after the direct threats on life have been taken away, the process of adaptation in a psychological way will have only just begun.

3.3.1.3 Integration of the traumatic event

The intention and function of this whole oscillatory process between intrusion and denial becomes manifest in the last phase. What the individual ultimately has to do is integrate the traumatic event, i.c. cancer, in his cognitive structure, i.e. in his way of perceiving and constructing the world. Horowitch refers to these concepts in terms of schemata. A schema is a central cognitive structure in perception. It belongs to the observer, it can be changed by experiences and it is rather specific to every individual. The schema determines what is perceived, because information can be picked up only when there is a developing format ready to accept it. When an individual is confronted with new information which is of great significance to him but which does not match his own schemata, a state of discongruence arises, which has two direct consequences:

1) this state leads to strong emotional reactions
2) a dynamic process starts to abolish this state of discongruence which could be defined as the process of adaptation.

Repetition of the event, or parts of it, e.g. confrontation with the diagnosis, or the first course of chemotherapy, is needed to restore the feeling of being in control of the situation. Only then, when cognitive congruence is restored, can the process of adaptation stop and the emotions loose their impact on daily functioning. This, of course, does not mean that the event has been wiped out of the individuals memory. It simply means that it has been integrated into the person's life and control over his/her behaviour has been restored. Strong emotions are characteristic of disturbances in the process of coping. Fear of recurrence of the disease (the Damocles syn-

drome), feelings of guilt, anger and grief often manifest themselves. Complaints suffered by many cured cancer patients are: sleeping disorders, nightmares, concentration and memory disturbances, mood disturbances such as depression and back of enjoyment and physical tension such as headaches, hyperventilation and fatigue.

3.3.2. Determinant factors

In their theory on adaptation, Kleber et al. emphasize two points, firstly the fact that the consequential behaviour of a person after a traumatic experience varies considerably between individuals and secondly the fact that empirical studies indicate the presence of only a weak relationship between stress and psychological disorders.

According to Lazarus[104] the key feature, for explaining these phenomena lies in the assumption that cognitive activity - evaluative perceptions, thoughts and inferences - is used by the individual to interpret and guide every adaptational interchange with the environment. The person is assumed to "appraise" each ongoing and changing transaction within his/her environment with respect to its significance to well-being. This appraisal includes judgments (conscious or unconscious) on environmental demands and constraints (primary appraisal) as well as on the person's resources and options for managing them (secondary appraisal).

A central aspect in Lazarus' concept of coping is the notion of a transactional or bidirectional relationship between person and environment. A person thinks and acts, and thereby alters the situation, which in turn influences the person's way of thinking and acting, and so on.

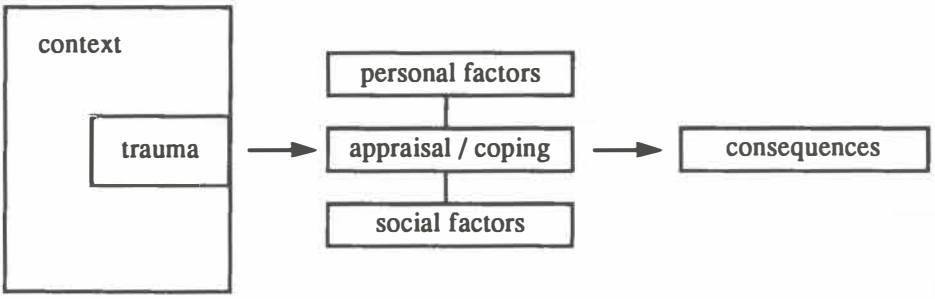
Figure 3.1 The bidirectional relationship between person and environment (after Schaufeli[105]).

It is this transactional nature which no longer makes coping simply a response to an event that has happened, but instead making it into an active force by shaping what is happening and what will happen[105]. This cognitive process of coping is complex and highly symbolic, permitting the individual to distinguish between actual harm or loss, (future) threat and challenge and to make many other subtle cognitive distinctions that give our lives their highly rich and complex emotional qualities.

Although there is elaborate empirical support for the mediating role of cognitive processes in psychological stress and although the general principle is widely accepted by many psychologists, the nature of the link between cognitive processes, adaptational behaviour and physiological outcomes remains obscure. Kleber et al. have adopted Lazarus' idea of coping or appraisal as the key feature for explaining weak relationships between stressors and individual outcome behaviour but they

furthermore emphasize that coping or appraisal itself should be regarded as part of a larger interactional system. Apart from the above-mentioned stressor, appraisal and consequential behaviour, they have isolated three main groups of co-determining factors:

1) the context; aspects of the situation in which the event took place
2) personal factors; characteristics of the specific individual
3) social and cultural factors.

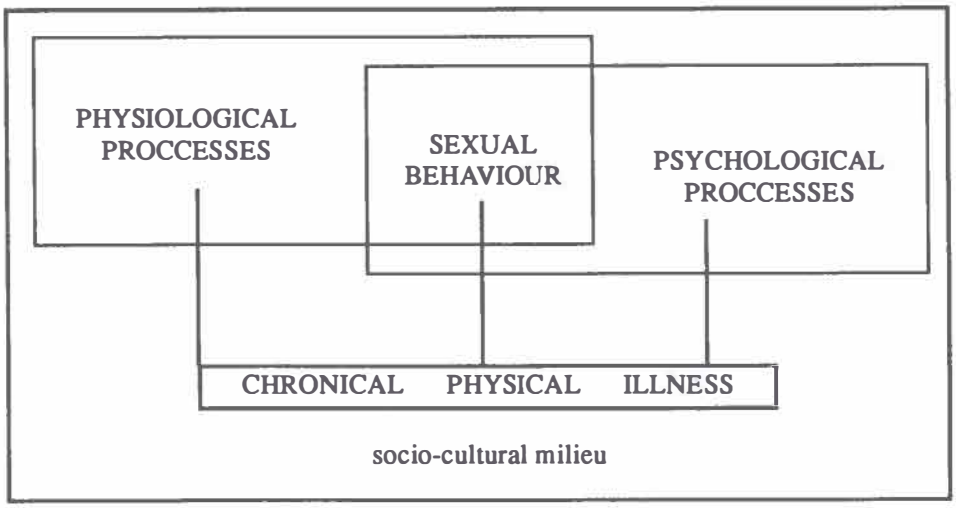


In this model, appraisal or coping is part of a larger interactional system in which all factors, including coping influence one another.

The system as a whole has a transactional character, like coping, which means that the "consequences" at time 1 can also be substituted for "trauma" at time 2. This also means that the mediating effect of coping is mediated by other psychological and social factors and vice versa. Distinctions between the several phases of the adaptation process or between determining factors are therefore hard to make. Maybe this is one of the reasons why Lazarus' transactional model based on a circular rather than a lineair kind of causality, has never been used in research on sexual functioning after traumatic medical events, such as e.g. gynaecological cancer treatment.

3.3.3 Specific psychological reactions to gynaecological cancer in relation to sexuality

The purpose of this paragraph is to examine the psychological processes of adaptation after gynaecological cancer treatment with special emphasis on sexual behaviour. Beutler[107] stated:" Neither psychopathology nor organic pathology can always be expected to underlie sexual dysfunction in cancer patients...sexual dysfunction represents the final common pathology of biological, social, and psychological factors in the patient's personal and interpersonal world". Anderson and Wolf[108] propose the following, rather simple heuristic model in which the interactions and influences between chronic disease (i.c. genito-urinary malignancies) and sexual behaviour are represented:



Anderson and Wolf's model is also based on a transactional point of view which means that psychological distinctions may be effects as well as causes of sexual dysfunction. Furthermore, they emphasize that other characteristics may be associated with the presence of dysfunction through mutual association with a third factor.

In their review, Anderson and Wolf summarize a number of psychological reactions to genito-urological cancer that may form a threat to sexual functioning:

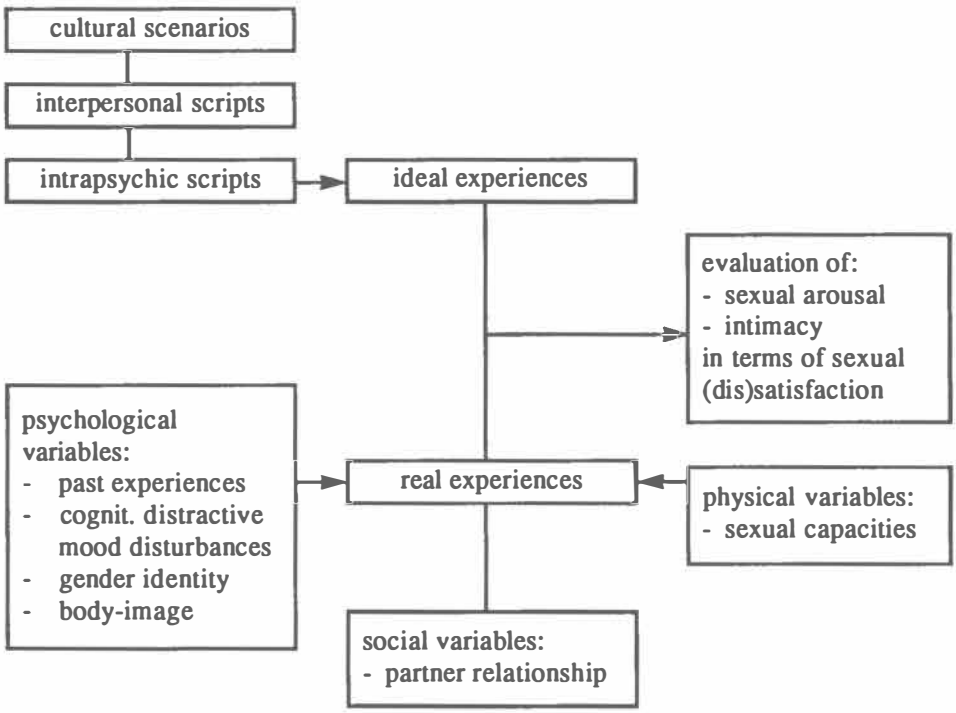
1) **threats to sexual identity and self-esteem:**
   - mood disturbances, such as fear, anxiety, depression or anger;
   - disturbances of gender and sexual identity - in the sense of viewing and defining oneself as male or female;
   - disturbances of body-image, i.e. the perception of how we appear physically and the value we assign to our physical desirability;
2) **threats to personal control over body functions:**
   - directly by impairment of the sexual systems involved;
   - indirectly by other disease-related symptoms that interfere with or inhibit sexual functioning;
3) **threats to intimacy:**
   - loss of social contacts, especially those with the potential for intimate physical expressions and social isolation;
   - disintegration of established patterns for achieving physical pleasure and intimacy;
   - myths and misinformation about sexual behaviour in relation to the disease, e.g. the belief that cancer or radiation from the treatments may be contagious, or the idea that sexual activity may involve increased risk for the (ex)patient;
4) **threats to generativity:**
   - directly by impairment of fertility, interference with sexual functioning or high-risk pregnancy;
   - indirectly by fear of transmitting the disease or fear of dying before the child has grown up.

To summarize, genito-urinary malignancies threaten at least four basic personal resources which are all mutually related: sexuality and self-esteem, control over sexual responses and body functions, intimacy and generativity.

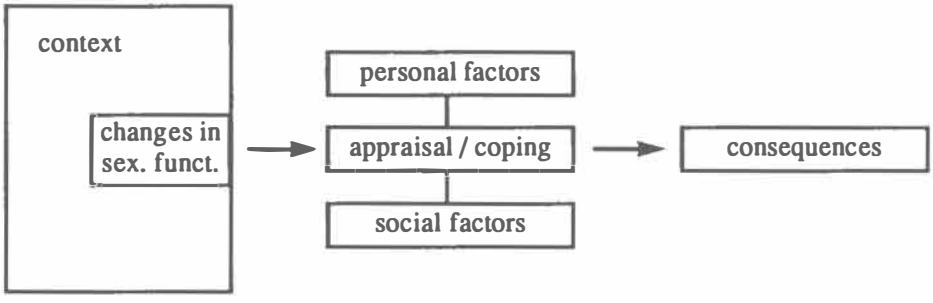
Although empirical evidence is lacking, individuals could be expected to experience less joy and vigor, as well as more anxiety/fear, sadness/depression, anger, confusion, fatique and other mood disturbances as a result of increased awareness of their disease. These psychological consequences of the disease and its treatment can be linked, antecedent or consequent, to disturbances in sexual function.

3.3.4 An integrative model for sexual functioning after gynaecological cancer treatment

In combination with the psychological reactions to genito-urinary i.c. gynaecological cancer treatment as described by Anderson and Wolfe, the following more detailed model can be hypothesized:



This model of sexual functioning on its turn can be substituted in the general model for adaptation after traumatic events:



This integrated model makes it clear that on a psychological level not all changes in sexual functioning after gynaecological cancer treatment automatically lead to sexual problems or dysfunctions. Whether sexual dissatisfaction occurs will also depend on personal factors, social factors and the context in which these (negative) changes occur.

REFERENCES

1. AALDERS, J.G. (1982) Prognostic factors and treatment of endometrial carcinoma. Groningen, Dissertation.
2. Annual report on the results of treatment in gynaecological cancer. (1985) International Federation of Gynecology and Obstetrics Radiumhemmet. Stockholm, 19, S 104-01.
3. BARENTS, J.W. et al. (1983) Het ovariumcarcinoom. Alphen a/dRijn/Brussel, Stafleu.
4. BLAUSTEIN, A. (1982) Pathology of the Female Genital Tract (2nd edition). New York, Springer.
5. Dutch Society of Gynaecologic Oncology (1985) Gynecologic cancer morbidity. Leiden, Internal report.
6. FRIEDRIECH, E.G. (1983) Vulvar disease (2nd edition). Phyladelphia, Saunders.
7. HACKER, N.F. & JOCHIMSEN, P.R. (1986) In: B.L. Andersen (Ed.) Women with cancer, psychological perspectives. New York, Springer Verlag.
8. STOLK, J.G. & LAMMES, F.B. (1985) Vulvacarcinoom. In: G.J. Kloosterman et al. (Eds.) De Voortplanting van de mens. Leerboek voor Obstetrie en Gynaecologie. Weesp, Centen.
9. Stuurgroep Toekomstscenario's Gezondheidszorg (1987) Utrecht/Antwerpen, Bohn, Scheltema & Holkema.
10. ANDERSEN, B.L., LACHENBRUCH, P.A., ANDERSON, B. & DEPROSSE, C. (1986) Sexual dysfunction and signs of gynecologic cancer. Cancer, 57, pp. 1880-1886.
11. PATTERSON, R.H. & GRAIG, J.B. (1963) Misconceptions concerning the psychological effects of hysterectomy. American Journal of Obstetrics and Gynecology, 85, pp. 104-111.
12. BARKER, M.G. (1968) Psychiatric illness after hysterectomy. British Medical Journal, ii, pp. 571-580.
13. WRIGHT, R.C. (1969) Hysterectomy: past, present, and future. Obstetrics and Gynecology, 33, pp. 560-563.
14. RICHARDS, D.C. (1973) Depression after hysterectomy. Lancet, ii, pp. 430-432.
15. RICHARDS, D.C. (1974) A post-hysterectomy syndrome. Lancet, ii, pp. 983-985.
16. HAMPTON, D.J. & TARNASKY, W.G. (1974) Hysterectomy and tubal ligation: a comparison of the psychological aftermath. American Journal of Obstetrics and Gynecology, 119, pp. 949-952.
17. MEIKLE, S., BRODY, H. & PYSH, F. (1977) An investigation into the psychological effects of hysterectomy. Journal of Nervous Mental Disorders, 164, pp. 36-41.
18. DENNERSTEIN, L., WOOD, C. & BURROWS, G.D. (1977) Sexual response following hysterectomy and oophorectomy. Obstetrics and Gynecology, 49, pp. 92-96.
19. WIJMA, K. (1984a) Psychological functioning after hysterectomy. Groningen, Dissertation.
20. GIJSBERG VAN WIJK, C.M.T., KOLK, A.M.M., GROOT, R.P.W., BLEKER, O.P., KETTING, B.W. & LAMMES, F.B. (1987) Psychische en seksuele gevolgen van uterusextirpatie. Nederlands Tijdschrift voor Geneeskunde, 131, pp. 758-762.
21. BANCROFT, J (1983) Human sexuality and its problems. Edinburgh, Churchill Livingstone, p. 344.
22. WIJMA, K. (1984b) Psychological functioning after non-cancer hysterectomy: a review of methods and results. Journal of Psychosomatic Obstetrics and Gynecology, 3, pp. 133-154.
23. WOODS, N.F. (1979) Human sexuality in health and illness. St. Louis Toronto/London, The CV Mosby Company, pp. 335-340.

24. ZUSSMAN, L., ZUSSMAN, S., SUNLEY, R. & BJORNSON, E. (1981) Sexual response after hysterectomy-oophorectomy: Recent studies and reconsideration of psychogenesis. American Journal of Obstetrics and Gynecology, 140, pp. 725-729.
25. SINGER, I (1973) The Goals of human sexuality. London, Wildwood house.
26. PERRY, J.D. & WHIPPLE, B. (1982) Multiple components of the female orgasm. In: B. Graber (Ed.) Circumvaginal musculature and sexual function. Basel, Karger S, pp. 101-114.
27. HASPELS, A.A. (1979) Uterusextirpatie en orgasme. In: A. Musaph & A.A. Haspels (Eds.) Orgasmestoornissen bij de vrouw. Deventer, Van Loghum Slaterus, pp. 30-38.
28. RUBIN, P. & CASARETT, G.W. (1968) Clinical radiation pathology. Philadephia, Saunders WB and Company.
29. AMIAS, A.G. (1975) Sexual life after gynaecological operations. British Medical Journal, 2, pp. 608-609 and 680-681.
30. CASTALLO, M.A. & WAINER, A.S. (1950) Length of vagina following abdominal hysterectomy, total and subtotal. American Journal of Obstetrics and Gynecology, 60, p. 406-410.
31. JEWETT, J.F. (1952) Vaginal length and incidence of dyspareunia following total abdominal hysterectomy. American Journal of Obstetrics and Gynecology, 63, pp. 400-407.
32. KILKKU, P. (1983) Supravaginal uterine amputation vs hysterectomy. Effects on coital frequency and dyspareunia. Acta Obstetricia et Gynecologica Scandinavia, 62, pp. 141-145.
33. KILKKU, P., GRöNROOS, M., & PUNNONEN, R. (1982) Sexual function after conization of the uterine cervix. Gynecologic Oncology, 14, pp. 209-212.
34. KILKKU, P., GRöNROOS, M., HIRVONEN, T. & RAURAMO, L. (1983) Supravaginal uterine amputation vs hysterectomy. Effects on libido and orgasm. Acta Obstetricia et Gynecologica Scandinavia, 62, pp. 147-152.
35. POLIVY, J. (1974) Psychological reactions to hysterectomy: A critical review. American Journal of Obstetrics and Gynecology, 118, pp. 416-426.
36. KAUFERT, P. & SYROTNIK, J. (1981) Symptom reporting at the menopause. Social Science in Medicine, 15E, pp. 173-184.
37. MASTERS, W.H. & JOHNSON, V.E. (1966) Human sexual response. Boston, Little Brown and Company.
38. LEIBLUM, S., BACHMANN, G., KEMMANN, E., COLBURN, D. & SWARTZMAN, L. (1983) Vaginal atrophy in the postmenopausal woman. The importance of sexual activity and hormones. JAMA, 249, pp. 2195-2198.
39. PFEIFFER, E., VERWOERDT, A. & DAVIS, G.C. (1972) Sexual behavior in middle life. American Journal of Psychiatry, 128, pp. 1262-1267.
40. HäLSTRöM, T. (1977) Sexuality in the climacteric. Clinics in Obstetrics and Gynaecology, The Menopause. In: R.B. Greenblatt & J. Studd (Eds.) London, Saunders, 4, pp. 227-239.
41. DENNERSTEIN, L., BURROWS, G.D., WOOD, C. & HYMAN, G. (1980) Hormones and sexuality: Effect of estrogen and progestogen. Obstetrics and Gynaecology, 56, pp. 316-322.
42. VAUGHN, T.C. & HAMMOND, B.H. (1981) Estrogen replacement therapy. Clinical Obstetrics and Gynecology, 24, pp. 253-283.
43. BERGER, J. & BOSCHMAN, H.W. (1957) Symposium C: Androgen effect on vaginal epithelial cells. Acta Cytologica, 1, pp. 70-103.
44. SHERWIN, B.B., GELFAND, M.M. & BRENDER, W. (1985) Androgen enhances sexual motivation in females: a prospective, cross-over study of sex steroid administration in the surgical menopause. Psychosomatic Medicine, 47, pp. 339-351.

45. SHERWIN, B.B. & GELFAND, M.M. (1985) Differential symptom response to parenteral estrogen and/or androgen administration in the surgical menopause. American Journal of Obstetrics and Gynecology, 151, pp. 153-160.
46. SHERWIN, B.B. & GELFAND, M.M. (1987) The role of androgen in the maintenance of sexual functioning in oophorectomized women. Psychosomatic Medicine, 49, pp. 397-409.
47. BURGER, H., HAILES, J. & NELSON, J. (1987) Effect of combined implants of oestradiol and testosterone on libido in postmenopausal women. British Medical Journal, 294, pp. 937-937.
48. CARDOZO, L., GIBB, D.M.F., TUCK, S.M., THOM, M.H., STUDD, J.W.W. & COOPER, D.J. (1984) The effects of subcutaneous hormone implants during the climacteric. Maturitas, 5, pp. 177-184.
49. MELDRUM, D.R., DAVIDSON, W.B., TATARYN, I.V. & JUDD, H.L. (1981) Changes in circulating steroids with aging in postmenopausal women. Obstetrics & Gynecology, 57, pp. 624-628.
50. VERMEULEN, A. (1981) The hormonal activity of the menopausal ovary. Journal of Clinical and Endocrinologic Metabolism, 42, p. 247.
51. GOTTESMAN, D. & LEWIS, M.S. (1982) Difference in crisis reactions among cancer patients, Journal of Consulting and Clinical Psychology, 50, pp. 381-388.
52. NERENZ, D.R., LEVENTHAL, H. & LOVE, R. (1982) Factors contributing to emotional distress during cancer chemotherapy. Cancer, 50, pp. 1020-1027.
53. ANDERSEN, B.L. & TEWFIK, H.H. (1985) Individual differences in psychological responses to radiation therapy: A reconsideration of the adaptive aspects of anxiety. Journal of Personality and Social Psychology, 48, pp. 1024-1032.
54. ANDERSEN, B.L. (1985) Sexual functioning morbidity among cancer survivors. Current status and future research directions. Cancer, 55, pp. 1835-1842.
55. TWOMBLY, G.H. & LANDERS, D. (1956) The innervation of the bladder with reference to radical hysterectomy. American Journal of Obstetrics and Gynecology, 71, pp. 1291-1300.
56. FORNEY, J.P. (1980) The effect of radical hysterectomy on bladder physiology. American Journal of Obstetrics and Gynaecology, 138, pp. 374-382.
57. LOW, J.A., MANGER, G.M. & CARMICHAEL, J.A. (1981) The effect of Wertheim hysterectomy upon bladder and urethral function. American Journal of Obstetrics and Gynecology, 139, pp. 826-834.
58. SASAKI, H., YOSHIDA, T., NODAK, YACHIKU, S., MINAMI, K. & KANEKO, S. (1982) Urethral pressure profiles following radical hysterectomy. Obstetrics and Gynecology, 59, pp. 101-104.
59. MUNDY, A.R. (1982) An anatomical explanation for bladder dysfunction following rectal and uterine surgery. British Journal of Urology, 54, pp. 501-504.
60. DONKER, P.J. (1986) A study of the myelinated fibers in the branches of the pelvic plexus. Neurology and Urodynamics, 5, pp. 185-202.
61. WATSON, P.C. & WILLIAMS, D. (1952) The urological complications of excision of the rectum. British Journal of Surgery, 40, pp. 19-28.
62. GLAHN, B.E. (1970) The neurogenic factor of vesical dysfunction following radical hysterectomy for carcinoma of the cervix. Scandinavian Journal of Urology and Nephrology, 4, pp. 107-116.
63. SESKI, J.C. & DIOKNO, A.C. (1977) Bladder dysfunction after radical abdominal hysterectomy. American Journal of Obstetrics and Gynecology, 128, pp. 643-651.
64. ZANOLLA, R., MONZEGLIO, C., CAMPO, B., ORDESI, G., BALZARINI, A. & MARTINO G. (1985) Bladder and urethral dysfunction after radical abdominal hysterectomy: rehabilitative treatment. Journal of Surgical Oncology, 28, pp. 190-194.

65. WESTBY, M. & ASMUSSEN, M. (1985) Anatomical and functional changes in the lower urinary tract after radical hysterectomy with lymph node dissection as studied by dynamic urethrocystography and simultaneous urethrocystometry. Gynecologic Oncology, 21, pp. 261-276.
66. LEWINGTON, W. (1956) Disturbances of micturition following Wertheim's hysterectomy. Journal of Obstetrics and Gynaecology of the British Empire, 63, pp. 861-864.
67. FRASER, A.C. (1966) The late effects of Wertheim's hysterectomy on the urinary tract. Journal of Obstetrics and Gynaecology of the British Commonwealth, 73, pp. 1002-1007.
68. ASMUSSEN, M. & MILLER, A. (1983) Clinical gynaecological urology. Blackwell, Oxford.
69. KADAR, N., SALIBA, N. & NELSON, J.H. (1983) The frequency, causes and prevention of severe urinary dysfunction after radical hysterectomy. British Journal of Obstetrics and Gynaecology, 90, pp. 858-863.
70. PALM, L. & RONNIKE, F. (1970) Bladder function following either radiotherapy or radical operation ad modum Okabayashi for cervical cancer. Danish Medical Bulletin, 17, pp. 113-124.
71. ABITBOL, M.M. & DAVENPORT, J.H. (1974) The irradiated vagina. Obstetrics and Gynecology, 44, pp. 249-256.
72. SEIBEL, M., FREEMAN, M.G. & GRAVES, W.L. (1980) Carcinoma of the cervix and sexual functioning. Obstetrics and Gynecology, 55, pp. 84-487.
73. HUGHES, R.P. (1971) Early diagnosis and management of premalignant lesions and early invasive cancers of the vulva, Southern Medical Journal, 64, p. 1490.
74. FORNEY, J.P., MORROW, C.P., TOWNSEND, D.E. & DISAIA, P.J. (1977) Management of carcinoma in situ of the vulva. American Journal of Obstetrics and Gynecology, 127, pp. 801-806.
75. DISAIA, P.J. & CREASMAN, W.T. (1988) Clinical Gynecologic Oncology. Mosby.
76. DISAIA, P.J., CREASMAN, W.T. & RICH, W.M. (1979) An alternate approach to early cancer of the vulva. American Journal of Obstetrics and Gynecology, 133, pp. 825-832.
77. HOFFMAN, M., ROBERTS, W.S. & CAVANAGH, D. (1988) Neuropathies associated with radical pelvic surgery for gynecologic cancer. Gynecologic Oncology 31, pp. 462-466.
78. KAGAN, A.R., NUSSBAUM, H., GILBERT, H., CHAN, P.Y.M., RAO, A., SALTZ, A., TAWA, K. & WOLLINS, M. (1979) A new staging system for irradiation injuries following treatment for cancer of the cervix uteri. Gynecologic Oncology, 7, pp. 166-175.
79. TIMMER, P.R. (1982) De behandeling van het cervixcarcinoom in het Academisch Ziekenhuis Groningen van 1970 tot 1979. Groningen, Dissertation.
80. KOTTMEIER, H.L. (1981) Carcinoma of the uterine cervix - radiotherapy. In: Current Topics in Pathology, 70, pp. 237-252.
81. RUBIN, L. (1980) Psychological and physiological concept in female sexuality. In: M. Kirkpatrick (Ed.) New York, Plenum Press, pp. 77-81.
82. BERTELSEN, K. (1983) Sexual dysfunction after treatment of cervical cancer. Danish Medical Bulletin, 30 suppl 2, pp. 31-34.
83. HARTMAN, P. & DIDDLE, A.B. (1972) Vaginal stenosis following irradiation therapy for carcinoma of the cervix uteri. Cancer, 30, pp. 426-429.
84. VASICKA, A., POPVICH, N.R. & BRAUSCH, C.C. (1958) Postradiation course of patients with cervical carcinoma. A clinical study of psychic, sexual, and physical well-being of sixteen patients. Obstetrics and Gynecology, 11, pp. 403-414.

85. POMA, P.A. (1980) Postradiation vaginal occlusions. Nonoperative management. International Journal of Gynaecology and Obstetrics, 18, pp. 90-92.
86. JUSENIUS, K. (1981) Sexuality and gynecologic cancer. Cancer Nursery, 4, pp. 479-484.
87. BRANSFIELD, D. & HORIOT, J.C. (1984) Cervical cancer and sexual functioning: Practical suggestions for the radiotherapist. Journal of European Radiotherapy, 5, pp. 11-15.
88. GAETINI, A., DE SIMONE, M., URGESI, A., LEVIS, A. RESEGOTTI, A., RAGONA, R. & ANGLESIO, S. (1988) Lateral high abdominal ovariopexy: anoriginal surgical technique for protection of the ovaries during curative radiotherapy for Hodgkin's disease. Journal of Surgical Oncology, 39, pp. 22-28.
89. BEURDEN, M. VAN, SCHUSTER-UITTERHOEVE, A.L.J. & LAMMES, F.B. (1990) Feasibility of transposition of the ovaries in the surgical and radiotherapeutical treatment of cervical cancer. European Journal for Surgical Oncology, 16, pp. 141-146.
90. CHAPMAN, R.M., SUTCLIFFE, S.B. & MALPAS, J.S. (1979) Cytotoxic-induced ovarian failure in Hodgkin's disease II. Effects on sexual function. JAMA, 242, pp. 1882-1884.
91. CHAPMAN, R.M. (1982) Effects of cytotoxic therapy on sexuality and gonadal function. Seminars in Oncology, 9, pp. 84-94.
92. KAPLAN, S. & WIERNIK, P.H. (1982) Neurotoxiticity of anti-neoplastic drugs. Seminars in Oncology, 9, pp. 103-130.
93. PRESTAYKO, A.W., D'AOUST, J.C., ISSELL, B.F. & CROOKE, S.T. (1979) Cisplatin (cis-diammine dichloroplatinum II). Cancer Treatment Review, 5, pp. 17-39.
94. MAGUIRE, G.P., LEE, E.G., BEVINGTON, D.J., KUCHEMANN, C.S., CRABTREE, R.J. & CORNELL, C.E. (1978) Psychiatric problems in the first year after mastectomy. British Medical Journal, 1, pp. 963-965.
95. ANDERSEN, B.L. (1986) Sexual difficulties for women following cancer treatment. In: B.L. Andersen (Ed.) Women with Cancer, psychological perspectives. New York Springer Verlag, New York.
96. MASTERS, W.H. & JOHNSON, V.E. (1970) Human sexual inadequacy. Boston, Little Brown, pp. 286-287.
97. DAUT, R.L. & CLEELAND, C.S. (1982) The prevalence and severity of pain in cancer. Cancer, 50, pp. 1913-1918.
98. LATORRE, R.A. (1978) Gender role and psychological adjustment. Archives of Sexual Behavior, 7, pp. 89-96.
99. DEROGATIS, L.R. (1980) Breast and gynecologic cancers. Their unique impact on body-image and sexual identity in women, Frontiers in Radiation Therapy and Oncology, 14, Basel, Karger S, pp. 1-11.
100. MOOS, R.H.& SCHAEFER, J.A. (1984) The crisis of physical illness: an overview and conceptual approach. In: R.H. Moos (Ed.) Coping with physical illness: new perspectives. New York, Plenum Press, pp. 3-25.
101. KLEBER, R.J., BROM, D. & DEFARES, P.B. (1986) Traumatische ervaringen, gevolgen en verwerking. Lisse, Swets en Zeitlinger.
102. MAGNUSSEN, D. & ENDLER, N.S. (1977) Personality at the crossroads. Hillsdale (NJ), Lawrence Erlbaum Associates, pp. 3-36.
103. HOROWITCH, M.J. (1976) Stress response syndromes. New York, Jason Aronson.
104. LAZARUS, R.S. & LAUNIER, R. (1978) Stress-related transactions between person and environment. In: L.A. Pervis & M. Lewis (Eds.) Perspectives in interactional psychology. New York, Plenum Press, pp. 287-323.

105. SCHAUFELI, W. (1988) Unemployment and psychological health. Groningen, Dissertation.
106. ROSKIES, E & LAZARUS, R.S. (1980) Coping theory and the teaching of coping skills. In: P.O. Davidson & S.M. Davidson (Eds.) Behavioral Medicine: changing health life styles. New York, Brunner Mazel Inc., pp. 38-96.
107. BEUTLER, L.E. (1981) Psychological evaluation: its importance in treatment decisions. In: A.C. von Eschenbach & D. Rodriguez (Eds.) Sexual rehabilitation of the urologic cancer patient. Boston, Hall, pp. 174-190.
108. ANDERSEN, B.L. & WOLF, F.M. (1986) Chronic physical illness and sexual behavior: psychological issues. Journal of Consulting and Clinical Psychology, 54, pp. 168-175.

Chapter 4

Sexual outcome following female genital cancer treatment, a critical review of methods of investigation and results

4.1 Introduction

The purpose of this chapter is to give an insight into the literature about the sexual outcome of women treated for gynaecological cancer and to search for empirically-confirmed prognostic variables.

4.2 Methods

As a first step towards collecting suitable literature which has been published since 1950, a computer-based search was performed with the descriptors: gynaecological cancer, sexual functioning, sexual rehabilitation. As a second step, all the references given in the selected publications were examined.

The review, to be considered as a sequel to an earlier report on this issue,[62] is restricted to those reports which give comprehensible and clear-cut documentation of sampling procedures, methods of investigation and results. The publications were classified into two groups on the basis of the methods used : post-treatment studies (Table I) and pre-post-treatment studies (Table II). Apart from information on the sexual functioning of gynaecological cancer patients, these tables provide information on the country of origin of the studies, on methodological and statistical issues, such as assessment techniques, sample size and data analysis and a limited comment. To facilitate comparison, the results shown in the tables are generally expressed as percentages.

4.3 Results of post-treatment studies (Table I)

All the authors of the post-treatment studies in which each individual woman compared her preoperative and postoperative states retrospectively, reported that sexual functioning was considered to have deteriorated after treatment for gynaecological cancer. Sexual-functioning-morbidity estimates ranged from 6 to 100% of the patients surveyed. Post-treatment studies clearly revealed that despite major physical losses and substantial emotional disruption, the patients attempted to maintain a

W.C.M. Weijmar Schultz, D.D. Bransfield, H.B.M. van de Wiel & J. Bouma (1991). Accepted by Sexual and Marital Therapy.

sexual life.[33,38] Based on these studies, there are several prognostic variables which may be related to the presence of post-treatment sexual activity: the magnitude of surgical intervention,[37,38,41] the pretreatment libidinal level,[3] age and the presence of more lengthy stable relationships[17,35,41] and partner-related factors, such as availability, attitude and health.[8,18,35,44] Only 4 retrospective studies mentioned interviewing the sexual partner.[15,32,35,36]

The group that has received the greatest amount of interest from investigators of sexual functioning following gynaecological cancer treatment is the cervical cancer patient group. This is probably related to the large number of patients and to the controversy about which treatment modality better controls cervical cancer: radical hysterectomy with lymph node dissection versus radiation therapy. In terms of survival, the two modes of therapy are equally effective for early stage disease. Therefore the investigations have been focussed on determining whether the treatment modalities produce different rates of sexual disruption. All the retrospective investigations on this issue,[16,11,12,23,47] except for two,[9,26] did find a post-treatment difference in sexual disruption, to the detriment of radiation therapy. Kahanpää & Gylling[9] found the opposite, but the study is of limited value because of the methodological flaws. In the study by Tamburini et al,[26] no significant differences were found in sexual functioning between women treated with radical hysterectomy, radiotherapy or combined treatment.

After radical vulvectomy,[33,32,34,36,38] as many as 50 to 80% of the women have been found to stop all sexual activity. However, the women do not lose their desire for sexual activity[35,38] and, remarkably enough, in one retrospective study on sexual functioning after radical vulvectomy, 8 of the 10 participating couples accomplished complete or partial sexual rehabilitation and were satisfied with their sexual relationship.[35]

For women undergoing radical pelvic surgery the situation is worse.[39,41-44] Radical pelvic surgery (=anterior/posterior or total pelvic exenteration) is an extensive and disfiguring procedure which is usually performed in women with local recurrence of cancer in the pelvis, as a last curative attempt. In many cases it necessitates removal of the pelvic organs, including the bladder, rectum and vagina. Despite the various forms of stress which arise following radical pelvic surgery, especially those related to desexualization, the over-all level of social and psychological adjustment was favourable.[39,41,42,44]

Some investigators reported that the information provided by professional counselers about the sexual consequences of the disease and the treatment is insufficient[38,29], especially the information given to the partner.[32,35] Several authors emphasized the importance of sexual counseling both before and after the surgery which also involves the partner.[27,32,34,35,36]

4.4 Results of pre-post-treatment studies (Table II)

In the only pre-post-treatment study on sexual outcome after conization because of preinvasive cervical cancer, there were no significant declines in the frequency of

sexual intercourse or sexual satisfaction and no concomitant increases in sexual dysfunction.[45] In fact, reports of dyspareunia had decreased significantly at the 6 and 12 month post-treatment assessments, which according to the authors, was probably because the earlier cervicitis had been cured by the operation.

Irrespective of the kind of treatment, estimates of diminished or completely disrupted sexuality in pre-post-treatment studies on sexual outcome following treatment of invasive cervical cancers, range from 0-40%.[46,48,49,50,51]

In prospective studies focussing on differences in sexual functioning between women treated by surgery or radiotherapy,[46,48,50] only minor differences in pre- and post-treatment sexual functioning were measured between the two groups at the 6-month assessment. At the 12-month assessment, these studies showed conflicting results. In the study by Schover et al,[50] the radiotherapy group developed dyspareunia and had more problems with sexual desire and arousal than the radical-hysterectomy-alone group. However, in the study by Vincent et al,[46] no difference in sexual functioning was measured at the 12 month posttreatment assessment. In contrast to the study by Schover et al,[50] the patients in the treatment groups in the latter study were fairly similar because of random assignment to cancer therapy.

Andersen et al[51] performed a thorough prospective longitudinal study, in which they compared women with ovarian, cervical and endometrial cancer to healthy women and to women with benign gynaecological disease. They found a decline in the frequency of intercourse in the women treated for disease, but at the 8 and 12-month assessments, no further significant changes were observed on this point in comparison with healthy women. Changes occurred in the sexual response cycle, some of which persisted, in particular diminution of sexual excitement, which was more severe and distressing for the women with cancer. The authors attributed this to significant coital and postcoital pain, premature menopause, treatment side-effects, or a combination. Their data indicated that the arousal problems in the women with disease were not anxiety-based.

Only one pre-post-treatment study on sexual functioning after radical vulvectomy is available. In a prospective longitudinal study, Weijmar Schultz et al[58] found that within one year, all the women who were sexually active before the treatment, had resumed their sexual activities. At the 6-month assessment, an increase in relational sexual dissatisfaction could be detected. Over the remaining observation period, the women's satisfaction with sexual interaction with the partner was not found to be different from their pre-treatment satisfaction and not different from the satisfaction in an age-matched control group of healthy women, in spite of the physical damage and the persisting poor perception of genital symptoms of sexual arousal during love-making. The authors conclude that satisfaction with sexual interaction with the partner under these circumstances appears to be more an expression of satisfaction with the intimate aspects of the sexual relationship than of satisfaction with the physiological aspects of the sexual relationship. While interviewing the women one year after the treatment, it appeared that sexual rehabilitation itself is determined on a higher level, by a more general striving for balance in the relationship.[59] The men, when asked for 1 year after the treatment, stated that they experienced the process of providing support as a stressful job and had serious doubt about their provided

support.[60] The authors hypothesize that the disease and its treatment also poses a crisis for the partner, which leads to a regression towards a more rigid, male stereotype way of coping. Therefore, interventions to prevent or reduce sexual problems after gynaecological cancer treatment should not only be directed towards the patient, but also towards her partner and to their communication pattern.

Two pre-post-treatment reports have been published on sexual functioning after radical pelvic surgery. Dempsey et al[53] reported the cessation of sexual activity in 70% of the women after exenterative surgery. Lamont et al[52] demonstrated that if women "with good sexual attitudes and adjustments" have to undergo radical pelvic surgery and receive intensive counseling and vaginal reconstruction, a satisfying postoperative sexual relationship can be realized. They mentioned partner-education and his acceptation and interest as the most important factors in the process of achieving total sexual rehabilitation.

The sexually disruptive effects of symptoms prior to the discovery of gynaecological malignant disease have been studied by Harris et al[54] and Andersen et al.[55] The former study is of limited value because of the absence of statistical analyses, comparison groups and the lack of distinction between the different kinds of cancer. In a well-controlled investigation on women after diagnosis but before treatment of early stage cervical or endometrial cancer, Andersen et al[55] found substantial damage to sexual functioning in 75% of the women who were suffering from symptoms. Sexual problems included inhibited sexual desire (56%), inhibited sexual arousal (49%), inhibited orgasm (37%) and dyspareunia (37%).

Cain et al[56] studied the effect of diagnosis and treatment on sexual functioning within one month of diagnosis. As can be expected, their findings within such a short period showed that women who had a satisfying relationship before the disease, ceased to have sexual intercourse after diagnosis due to their own psychosocial reaction to the cancer and the treatment, but also on account of physician factors, e.g. they were told to abstain following surgery, or physical factors, e.g. they believed sexual intercourse would exacerbate vaginal bleeding or vaginal discharge!

4.5 Discussion

Methodological aspects Our review of the literature on sexual outcome following female genital cancer treatment which has been published since 1950, revealed 60 articles: 44 articles were classified as post-treatment studies and 16 as pre-post-treatment studies.

The main methodological problems we encountered while preparing this overview were:

1. incomplete data;
2. patient selection;
3. different treatment methods;
4. diverse moments of assessment: differences in time intervals between the moment of assessment and the gynaecological cancer treatment, of a few months to 10 years[8,11,12,17,18,20,30,32, 33,35,38,40,42,44] and even longer [2,9,10,13, 22,25,28,31,36,39] in

many cases. Sometimes the time interval was not even mentioned.[1,4] These post-treatment studies certainly raise questions about the "construction and reconstruction" of events;

5. criteria of the measurement method: psychosexual-function variables were usually assessed by non-standardized interviews or questionnaires. Only 9 out of the 44 retrospective studies[7,8,26,33,37,38,39,41,44] and 7 out of the 16 pre-post-treatment studies[50,51,55,56,57,58,59] used standardized scales to evaluate psychological and sexual functioning;
6. absence of control groups; and
7. the absence of statistical analyses: two-thirds of the studies did not report statistical analysis of significant differences, therefore it is difficult to interpret their findings beyond the selected samples. In the majority of studies, it is not clear whether significant differential treatment effects occurred and whether there were true differences between pre-treatment and post-treatment levels of sexual activity.

In view of the methodological problems found in the retrospective studies and the difficulties they created for interstudy comparison, the composite results of these studies are considered to be only "indicative".

Characteristically, pre-post-treatment studies include pre-treatment assessments and thus permit comparison between pre- and post-treatment data. However, it should be realized that a patient's sexual functioning prior to diagnosis may be influenced by the onset of cancer signs and symptoms.[55] The same applies to confrontation with the diagnosis of cancer without any signs or symptoms.[61] The data on sexual functioning after cancer treatment may be biased due to the possible occurrance of "response shift bias"[63] and a rehabilitative effect because of participation in the research project (i.e. the Hawthorne effect and exposure in vitro). The general use of comparison groups is being recommended for all these reasons. Of the 15 pre-post-treatment studies only 5 used such a comparison group.[51,55,56,58,59]

Results Post-treatment studies indicated that gynaecological cancers and their treatment frequently have a deleterious effect on sexual functioning. However, in the light of the results of pre-post-treatment studies, dealing with invasive cervical cancer in particular, a less dramatic and more differentiated picture can be drawn.

These studies show deterioration of sexual functioning, but only in as far as it concerns the symptomatic period preceding the discovery of gynaecological malignant disease and the period right after diagnosis and treatment. Beyond this period, the deterioration in sexual functioning is less extreme than in the post-treatment studies. This also applies to differences between the various treatment modalities. The difference between post-treatment and pre-post-treatment studies may be due to the different approach to women's sexual functioning by using more specific methods of operationalization and analysis in the pre-post-treatment studies. Moreover, as already mentioned, participation in a pre-post-treatment study may have indirectly encouraged the patients to discuss sexual matters and/or to remain sexually active after the treatment.

Few of the post-treatment studies or pre-post-treatment studies compared the physical examination findings to the current level of sexual functioning.[11,16,22,23,25,43,45,50,51,53,58] In cases were the physical status had been assessed, sexual dysfunction was often associated with postcoital bleeding and/or vaginal shortening or stenosis.[1,9,11,16,22,45,47,50,51] Furthermore, few studies have compared psychological variables with the current level of sexual functioning.[3,4,7,23,25, 33,41,44,47,51] No previous research designs have used psychophysiological instruments to clarify the exact relationship between the post-treatment physical status and sexual functioning.

Prognostic variables Although a large variety of prognostic variables are presented in the literature, there are very few definitive answers to the question regarding which internal and external causal factors elicit and control sexual behaviour.

The most convincing empirically-confirmed prognostic variables which should be incorporated into future research are: partner-related factors, such as availability, attitude, health and length of relationship[5,8,15,17,18,20,32,34,35,36,41,44,51a/b,52,54,58,59] and health-care-provider-related factors, such as patient education and/or counseling.[27, 29,32,34,35,36,38,51,52,57,58,59]

Other prognostic variables that warrant additional study include physical factors, such as dyspareunia, oestrogen deprivation, postcoital bleeding, vaginal shortening, stenosis or the magnitude of surgical intervention,[1,9,11, 16,21,22, 23,30,37,38,41,43,45,47,50,51] body-image,[7,23,33,41,44] pretreatment libidinal level,[3] anxiety[4,25,47,51a/b,56] motivation for sexual interaction[35,44,58,59] and age.[35,41]

A potentially important prognostic variable which is not mentioned in the literature might be sex-role rigidity. Incorporation of all these variables into well-designed and controlled studies could provide clearer directions for subsequent interventions aimed at the patient, her partner and her health care providers.

REFERENCES

1. PICHA, E. (1957) Uber das Sexualleben von Frauen nach Radiumbehandlung gynäkologischer Erkrankungen. Geburtshilfe und Frauenheilkunde, 17, pp. 81-90.
2. DA RUGNA, D. & BUCHHEIM, E. (1968) Die Invalidität nach der Behandlung gynäkologischer Karzinome. Gynaecologia, 166, pp. 138-156.
3. BREITNER,J (1975) Beeinflussung des Sexuallebens durch Radikaloperation und Bestrahlung beim Genital-Ca der Frau. Archives für Gynäkologie, 189, pp. 420-425.
4. WENDERLEIN, J.M. (1979) Sexualberatung bei krebsbehandelten Frauen, Empirische Studie an 308 Frauen einer gynäkologischen Tumor-Nachsorgesprechstunde. Fortschritte der Medizine, 97, pp. 506-512.
5. NOVOTNA, J. & TUCKOVA, H. (1979) Mental changes in women with gynecologic cancer. Neoplasma, 26, pp. 629-634.
6. PFLEIDERER, A., RICHTER, D., THIESSEN, P., KISSEL, U., TIMI, B & NOWARA, P. (1979) Aktuelle Probleme bei der Nachsorge von Patientinnen mit Karzinomen der Zervix und des Corpus uteri. Onkologie, 2, pp. 62-69.
7. ANDERSEN,B.L. & JOCHIMSEN, P.R. (1985) Sexual functioning among breast cancer, gynecologic cancer, and healthy women. Journal of Consulting and Clinical Psychology, 53, pp. 25-32.

8. BOS-BRANOLTE, G. (1987) Psychological problems in survivors of gynaecologic cancers, a psychotherapeutic approach. Leiden, Dissertation.
9. KAHANPää, V. & GYLLING, T. (1951) Uber den Zustand mit Strahlenbehandlung geheilten Kollumkarzinompatientinnen bezüglich des Geschlechtslebens. Annales Chirurgigiae et Gynaecologiae Fenniae, 3, pp. 189-193.
10. FROEWIS, J. & PICHA, E. (1955) Der Einfluss der Radikaloperationen bei Carcinoma colli uteri auf das Sexualleben der Frau mit besonderer Berücksichtigung der Wertheimschen operation. Geburtshilfe und Frauenheilkunde, 9, pp. 806-810.
11. VASICKA, A., POPOVICH, N.R. & BRAUSCH, C.C. (1958) Postradiation course of patients with cervical carcinoma. A clinical study of psychic, sexual, and physical well-being of sixteen patients. Obstetrics and Gynecology, 11, pp. 403-414.
12. DECKER, W.H. & SCHWARTZMAN, E. (1962) Sexual function following treatment for carcinoma of the cervix. American Journal of Obstetrics and Gynecology, 83, pp. 401-405.
13. LAU, H.U. (1967) Rehabilitation bei Kollumkarzinomkranken. Zentralblatt für Gynäkologie, 45, pp. 1649-1654.
14. ERKRATH, F.A. & RANDOW, H. (1967) Vita sexualis nach Karzinombehandlung im Vergleich zu nicht krebskranken, berufstätigen Frauen. Zentralblatt für Gynäkologie, 33, pp. 1210-1216.
15. LINDNER, E., PECKA, V. (1969) Sexualni zivot zen po lecbe zhoubnych nadoru rodidel. Cs. Gynekologie, 34, pp. 610-612.
16. ABITBOL M.M. & DAVENPORT J.H. (1974) The irradiated vagina. Obstetrics and Gynecology, 44, pp. 249-256.
17. ALHA A.L. & NIEMINEN, U. (1974) Psychological and somatic disturbances following combined treatment of cervical carcinoma. Annales Chirurgiae et Gynaecologiae Fenniae, 63, pp. 166-171.
18. HENNING, G. & SCHULZ, St. (1975) Sexualverhalten von Patientinnen nach der therapy von Zervixkarzinomen. Zentralblatt für Gynäkologie, 97, pp. 1562-1570.
19. KOS, L. (1978) Vpliv radikaknih ginekoloskih operacij na seksualno zivljenje pacientk. Jugoslavenska Ginekologija Obstetrija, 18, pp. 155-160.
20. BECK, A. & NIKOROVICZ (1980) Das Sexualleben nach Radikaloperationen des Zervixkarzinoms. Onkologie, 3, pp. 26-30.
21. SEIBEL, M., FREEMAN, M.G. & GRAVES, W.L. (1980) Carcinoma of the cervix and sexual functioning. Obstetrics and Gynecology, 55, pp. 484-487.
22. MORF, P.A., SPINELLI, A. & SAVOLDELLI (1980) Die Invalidität nach der Strahlentherapie des Kollumkarzinoms Stadium II und III. Strahlentherapie, 156, pp. 84-87.
23. SEIBEL, M., FREEMAN, M.G. & GRAVES, W.L. (1982) Sexual function after surgical and radiation therapy for cervical carcinoma. Southern Medical Journal, 75, pp. 1195-1197.
24. BERTELSEN, K. (1983) Sexual dysfunction after treatment of cervical cancer. Danish Medical Bulletin, 30 suppl 2, pp. 31-34.
25. FRANK, H., NIELSEN, A. & SJOLANDER, L. (1983) Livmoderhalskraeft. Ugeskrift for Laeger, 145, pp. 1317-1322.
26. TAMBURINI, M., FILIBERTI, A., VENTAFRIDDA, V., BIANCHI, F. & VOLTERRANI (1985) Emotional status, sexuality and quality of life in patients treated for carcinoma of the uterine cervix. Cervix, 2, pp. 261-267.
27. LASNIK, E. & TATRA, G. (1986) Sexualverhalten nach primärer Strahlentherapie des Zervixkarzinoms. Geburtshilfe und Frauenheilkunde, 46, pp. 813-816.
28. WALCHER, W., RALPH, G., LAHOUSEN, M., SCHEER, I, TAMUSSINOA & ROLLET (1988) Sexualitäat nach Radikaloperationen. Zentralblatt für Gynäkologie, 110, pp. 1109-1116.

29. JENKINS, B. (1988) Patient's reports of sexual changes after treatment for gynaecological cancer. Oncology Nursing Forum, 15, pp. 349-354.
30. DISAIA, P.J., CREASMAN, W.T. & RICH, W.M. (1979) An alternative approach to early cancer of the vulva. American Journal of Obstetrics and Gynecology, 133, pp. 825-832.
31. CHOO, Y.C. (1982) Invasive squamous carcinoma of the vulva in young patients. Gynecologic Oncology, 13, pp. 158-164.
32. MOTH, I., ANDREASSON, B., JENSEN, S.B. & BOCK, J.E. (1983) Sexual function and somatopsychic reactions after vulvectomy. Danish Medical Bulletin, 30, pp. 27-30.
33. ANDERSEN, B.L. & HACKER, N.F. (1983b) Psychosexual adjustment after vulvar surgery. Obstetrics & Gynecology, 62, pp. 475-462.
34. STELLMAN, R.E., GOODWIN, J.M., ROBINSON, J., DANSAH, D. & HILGERS, R.D. (1984) Psychological effects of vulvectomy. Psychosomatics, 25, pp. 779-783.
35. WEIJMAR SCHULTZ, W.C.M., WIJMA, K., WIEL, H.B.M. VAN DE, BOUMA, J. & JANSSENS, J. (1986) Sexual rehabilitation of radical vulvectomy patients, a pilot study, Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 119-126.
36. ANDREASSON, B., MOTH, J., JENSEN, S.B. & BOCK, J.E. (1986) Sexual function and somatopsychic reactions in vulvectomy-operated women and their partners. Acta Obstetricia et Gynecologica Scandinavia, 65, pp. 7-10.
37. TAMBURINI, M., FILIBERTI, A., VENTAFRIDDA, V. & DEPALO, G. (1986) Quality of life and psychological state after radical vulvectomy. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 263-269.
38. ANDERSEN, B.L., TURNQUIST, D., LAPOLLA, J. & TURNER, D. (1988) Sexual functioning after treatment of in situ vulvar cancer: preliminary report. Obstetrics & Gynecology, 71, pp. 15-19.
39. BROWN, R.S., HADDOX, V., POSADA, A. & RUBIO, A. (1972) Social and psychological adjustment following pelvic exenteration. American Journal of Obstetrics and Gynecology, 114, pp. 162-171.
40. MORLEY, G.W., LINDENAUER, S.M. & YOUNGS, D. (1973) Vaginal reconstruction following pelvic exenteration: Surgical and psychological considerations. American Journal of Obstetrics and Gynecology, 116, pp. 996-1002.
41. SEWELL H.H. & EDWARDS D.W. (1980) Pelvic genital cancer: body image and sexuality. Frontiers of Radiation Therapy and Oncology, Basel, Karger S., 14, pp. 35-41.
42. VERA, M.I (1981) Quality of life following pelvic exenteration. Gynecologic Oncology, 12, pp. 355-366.
43. MAGRINA, J.F. & MASTERSON, B.J. (1981) Vaginal reconstruction, procedures following radical pelvic surgery. Journal of the Kansas Medical Society, 82, pp.61-63.
44. ANDERSEN, B.L. & HACKER, N.F. (1983a) Psychosexual adjustment following pelvic exenteration. Obstetrics & Gynecology, 61, pp. 331-338.
45. KILKKU, P., GRöNROOS, M. & PUNNONEN, R. (1982) Sexual function after conization of the uterine cervix. Gynecologic Oncology, 14, pp. 209-212.
46. VINCENT, C.E., VINCENT, B., GREISS, F.C. & LINTON, E.B. (1975) Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
47. ADELUSI, B. (1980) Coital function after radiotherapy for carcinoma of the cervix uteri. British Journal of Obstetrics and Gynaecology, 87, pp. 821-823.
48. HANSEN, M.K. (1981) Surgical and combination therapy of cancer of the cervix uteri stages Ib and IIa. Gynecologic Oncology, 11, pp. 275-287.
49. POULSEN, H.K., KRISTENSEN, G.B. & HANSEN, M.K. (1983) Seksuel dysfuncktion efter operation for cancer cervicis uteri stadium IB og IIA. Ugeskrift for Laeger, 145, pp. 162-164.

50. SCHOVER, L.R., FIFE, M. & GERSHENSON, D.M. (1989) Sexual dysfunction and treatment for early stage cervical cancer. Cancer, 63, pp. 204-212.
51a. ANDERSEN, B.L., ANDERSON, B. & DEPROSSE, C. (1989) Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. Journal of Consulting and Clinical Psychology, 57, pp, 683-691.
51b. ANDERSEN, B.L., ANDERSON, B. & DEPROSSE, C, (1989) Controlled prospective longitudinal study of women with cancer: II. Psychological outcomes. Journal of Consulting and Clinical Psychology, 57, pp. 692-697.
52. LAMONT, J.A., DE PETRILLO, A.D. & SARGEANT, E.J. (1978) Psychosexual rehabilitation and exenterative surgery. Gynecologic Oncology, 6, pp. 236-242.
53. DEMPSEY, G.M., BUCHSBAUM, H.J. & MORRISON, J. (1975) Psychosocial adjustment to pelvic exenteration. Gynecologic Oncology, 3, pp. 325-334.
54. HARRIS, R., GOOD, R.S. & POLLACK, L. (1982) Sexual behavior of gynecologic cancer patients. Archives of Sexual Behavior, 11, pp. 503-510.
55. ANDERSEN, B.L., LACHENBRUCH, P.A., ANDERSON B. & DEPROSSE (1986) Sexual dysfunctions and signs of gynecologic cancer. Cancer, 57, pp. 1880-1886.
56. CAIN, E.N., KOHORN, E.I., QUINLAN, D.M., SCHWARTZ, P.E., LATIMER, K. & ROGERS, L. (1983) Psychosocial reactions to the diagnosis of gynecologic cancer. Obstetrics & Gynecology, 62, pp. 635-641.
57. CAPONE, M.A., GOOD, R.S., WESTIE, K.S. & JACOBSON, F. (1980) Psychosocial rehabilitation of gynecologic oncology patients. Archives of Physical Medicine and Rehabilitation, 61, pp. 128-132.
58. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, BOUMA, J., JANSSENS, J. & LITTLEWOOD, J. (1990) Psychosexual functioning after the treatment of cancer of the vulva: a longitudinal study. Cancer, 66, pp. 402-407.
59. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G., BOUMA, J. & VERHOEVEN, A.C. (1990) Sexual functioning of women treated for cancer of the vulva. Sexual and Marital Therapy, 5, pp. 73-82.
60. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., WOUDA, J. & BOUMA, J. (1990) Sexual functioning of partners of gynaecological oncology patients; a pilot study on involvement, support, sexuality and relationship. Sexual and Marital Therapy, 5, pp. 123-130.
61. WIEL, H.B.M. VAN DE & WEIJMAR SCHULTZ, W.C.M. (1985) Psychoseksuele reacties op de diagnoses gynaecologische kanker. Nederlands Tijdschrift voor Geneeskunde, 129, p. 2239.
62. BRANSFIELD, D.D. (1984) Psychosexual functioning after treatment for gynecologic malignancy. Yeshiva, Dissertation, Dissertation Abstract International (1985), 45 (12B), p. 3990.
63. HELSON, H. (1964) Adaptation-level theory: an instrumental and systematic approach of behavior. New York, Harper S.
64. BANCROFT, J. (1983) Human sexuality and its problems. Edingburgh/London, Churchill Livingstone.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
"Gynaecological malignancy"						
Picha (1957)[1] Austria	Cohort of 256 women treated for cervical cancer (156), endometrial cancer (50), ovarian cancer (16), cancer of the vagina (28)	(a) Irradiation	-	-	irradiated group	interview
		(b) Wertheim	-	-	older than operated	
		(c) Schauta-Amreich	-	-	group	
Da Rugna & Buchheim (1968)[2] Switzerland	Cohort of 418 women treated for cervical cancer (184), endometrial cancer (130) ovarian cancer (65), vaginal cancer (21) and vulvar cancer (18)	-	418	-	-	interview
Breitner (1975)[3] West Germany	Cohort of 82 women treated for cervical (57%), endometrial (29%), ovarian (10%) and vaginal cancer (2%)	(a) surgery-radiation therapy	57	-	52	interview
		(b) radiation therapy alone	25	-		
		Prior to treatment				
		(c) no libido	28			
		(d) low libido	37			
		(e) high libido	17			

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results				Comment
-	-	Unchanged anatomical capacity for sexual intercourse	(a) 74%	(b) 59%	(c) 33%	Though visual inspection of the results allude to a significant differential treatment effect, the absence of statistical analysis impedes accurate interpretation.
		marked difficulties	23%	34%	53%	
		no physical capacity for intercourse	3%	7%	26%	
7-11	-	Normal sexual intercourse		23%		Conclusions are not justified, given the research design so many years post-treatment.
		Dyspareunia		12%		
		Discontinued sexual relationship		22%		
		Breakdown of marriage		6.5%		
4	-	Post-treatment:	(c)	(d)	(e)	Results may indicate that pre-treatment libidinal level is one of the best predictors of post-therapy sexual functioning. The lack of libido is remarkable. The study's conclusion that psychological factors were responsible for the sexual dysfunction is refutable because interpretation was made without regard to cancer type or stage, amount or type of radiation, the patient's general health status, or vaginal condition.
		no intercourse	46%			
		anorgasmic	100%			
		unchanged libido		57%	71%	
		less libido		38%	18%	
		more libido		5%	12%	
		There was no difference in sexual functioning between the treatment groups. Within the total sample, approximately 12% reported having dyspareunia but continued to have intercourse to please their partners.				

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Wenderlein, Prötzel & Lehr (1979)[4] West Germany	Cohort of 308 women treated for cancer of the breast and genital cancer	(a) breast cancer	146	-	-	interview
		(b) genital cancer	162	-		
Novotna & Tuckova (1979)[5] Czecko-slovakia	Cohort of 126 women treated for gynaeco-logical malignancies	-	126	36	58	47-item self-report question-naire

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results			Comment
-	+	Anxiety about sexual activity	(a)	(b)	The only question posed to the women about their sexual functioning was whether they experienced anxiety about their sexual activity. Nevertheless the author concluded that patients with gynaecological cancer have a 50% higher incidence of sexual problems than mastectomy patients.
		Yes	16%	38%	
		No	44%	32%	
		No response	40%	30%	
2-3	-	Deteriorated sex life	33%		The authors stated that gynaecological cancer "does not pose any particular difficulties in the assessment, self-assessment or mode of sex life in most of the patients, except perhaps for young women or women living in unstable relationship anyway". This conclusion appears speculative, however, and cannot be affirmed, given the research design and the absence of statistical analysis for levels of significant difference.
		No changes	67%		

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Pfleiderer, Richter, Thiessen, Tun & Nowara (1979)[6] West Germany	Cohort of 100 women treated for gynaecological malignancies (cervical and endometrial cancer)	-	99	99	-	interview
Andersen & Jochimsen (1985)[7] U.S.A.	Cohort of 16 women treated for breast cancer stage II and 16 women treated for gynaecological cancer (cervix n=5 stage I, n=4 stage II; endometrium n=6 stage I; ovary n=1 stage I)	(a) breast cancer/ surgery and chemotherapy	16	94	48	self-report questionnaires and a 1-hour individual structured interview
		(b) gynaecological cancer/surgery	9	96		
		(c) gynaecological cancer/radiotherapy with prior staging laparotomy and/or intracavitary caesium implants	7	96		
		(d) healthy outpatients	16	85		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results		Comment
2-4	-	Libido decreased No intercourse Orgasmic response	60% <age 50< 48% 35% (before 22%) 57% (before 79%)	The absence of statistical analysis impedes accurate interpretation.
on average 7 months post-treatment	+	Specific aspects of sexual functioning for cancer patients that differed from those of healthy women, were the frequency of sexual behaviour and the level of sexual arousal. In contrast, the women with breast cancer or gynaecological cancer reported no differential responses on the indicants of sexual desire or orgasm. There were no significant differences between the breast cancer sample and gynaecological cancer sample as a function of length of time since treatment or for the interaction of time and cancer site. 82% of the gynaecological cancer sample reported poorer body-image evaluation, in contrast to 31% of the breast cancer patients and 38% of the women in the healthy samples.		These data suggest that body-image disruption may be a more prevalent problem in gynaecological cancer patients than in breast cancer patients, but it may exert little influence on sexual functioning. More of gynaecological cancer patients with disrupted body-image reported positive evaluations of their current sexual life than negative evaluations. The authors state that for methodological reasons, these results are only suggestive. Other important differences among the three groups might have existed. However, these data are noteworthy in that significant reductions in specific phases of the sexual response cycle were found.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Bos-Branolte (1987)[8] The Nether-lands	Cohort of 69 women treated for ovarian cancer (29), cervical cancer (24), endometrial cancer (12) and vulvar cancer (4)	-	69	76	50 (26-70)	semi-structured interview and question-naire

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assess-ment post-treatment in years	Statistical analysis	Results	Comment
0.5-7	+	Results showed a decrease in sexual activity (59%) and intimacy (22%) and an increase in needs for intimacy (19%), emotional support (30%) and open communcation (23%). Besides, 30% of these women were of the opinion that there was a negative change in sexual activity in their partners. A considerable number of women had the impression that, although their partners needed emotional support during their illness, they did not receive this kind of support. A positive partner relationship seemed to be more determined by intimacy, emotional support and open communication than by sexuality.	Given the aim of the study (evaluation of psycho-therapy) no general conclusions about treatment outcome can be drawn from these data.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Cervical cancer						
Kahanpää & Gylling (1951)[9] Finland	Cohort of 129 women treated between 1937 and 1945 for cervical cancer stages I-III	irradiation (a)	97	88	<50	self-report questionnaire
		radical hysterectomy (b)	32	80		
Froewis & Picha (1955)[10] Austria	Cohort of 544 women treated between 1939 and 1951 for cervical cancer	(a) Schauta-Amreich(vaginal approach)	51	55	30% < 50	interview
		(b) Wertheim (abdominal approach)	333	74		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results			Comment
5-13	-	Post-treatment level of sexual activity	(a)	(b)	In contrast to most other studies on this issue, a higher incidence of sexual disability was found among surgical subjects compared to irradiated subjects. The authors attribute their findings to the more optimal vaginal condition after irradiation than after radical hysterectomy (they assume but do not measure that during radical hysterectomy most of the vagina is removed) and to psychological factors: the surgical patients were conscious of having had their "feminine organs" removed unlike the irradiation subjects.
		satisfactory	43%	19%	
		moderately satisfactory	36%	31%	
		no sexual activity	21%	50%	
		Vaginal condition was found to be satisfactory (>8 cm) in 76% of the radiotherapy group.			
4-16	-		(a)	(b)	The study incorporates a large population but the results are of limited value because of methodological flaws (subjective nature of the study, moment of assessment, paucity of information).
		no sexual intercourse	23%	35%	
		unchanged frequency	23%	38%	
		dyspareunia	38%	22%	
		no coitus because of vaginal shortening or narrowing	15%	5%	
		no libido	29%	18%	
		libido unchanged	48%	78%	
		minimal libido	23%	4%	
		correction in relation to partner availability: unchanged coital frequency	31%	7%	
		anorgasmia	32%	23%	

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Vasicka, Popovich & Brausch (1958)[11] U.S.A.	Cohort of 16 women treated for cervical cancer stages I and II	irradiation	16	-	42 (30-51)	interview and pelvic examination
Decker & Schwartzman (1962)[12] U.S.A.	Cohort of 78 women treated for cervical cancer and for CIS of the cervix	(a) irradiation	29	-	(a) 50 (b) 45 (c) 41	interview
		(b) radical hysterectomy	32	-		
		(c) total hysterectomy	17	-	(29-73)	
Lau (1967)[13] West Germany	Cohort of 434 women treated for cervical cancer	(a) radiation therapy	83	-	-	interview
		(b) surgery	341		(20-80)	

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results				Comment
1-9 years post-treatment	-	Sexual impairment because of vaginal compromise or dyspareunia		13%		Because of the small sample and population characteristics, these findings cannot be generalized. Yet, the study is particularly instructive because it defines physical examination measurement techniques.
		diminished frequency of intercourse		44%		
		There was no indication of altered libido in a characteristic fashion following radiation treatment.				
0.5-10	-	Sexual functioning	(a)	(b)	(c)	From this investigation radiation therapy appears to cause a higher incidence of sexual incapacity than operation. However, age disparity and a 2 year difference in the treatment/interview time interval may have biased the outcome. Also, other treatment-related variables, not measured in this study, might be involved, e.g. patient and partner fears about radiation, perception of radiotherapy as a curative treatment.
		unchanged	34%	50%	71%	
		diminished or abolished	55%	19%	12%	
7-16	-	Reduced libido		53%		For statistical reasons the author's conclusion that "radiation is more damaging to coital capacity than surgery" is not justified.
				(a)	(b)	
		No more intercourse		35%	22%	
		Dyspareunia		25%	32%	

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Erkrath & Randow (1967)[14] West Germany	Cohort of 141 women treated for cervical cancer stages I and II and 895 healthy women	(a) Schauta-Stoeckel with radiotherapy	123		-	interview
		radiotherapy alone	18		(31-55)	
		(b) healthy women	895			
Lindner & Pecka (1969)[15] Czecho-slovakia	Cohort of 71 women treated for cervical and endometrial cancer	(a) surgery-radiation therapy	65	-	41-50	interview
		(b) radiation alone	6	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results			Comment
2-4	-	Discontinued sexual relationships 1/3 because of dyspareunia Libido unchanged Libido decreased Libido increased	(a) 35% 50% 39% 12%	(b) 17.3%	Results are of limited value because of methodological flaws (subjective nature of the study, moment of assessment, paucity of information).
-	-	Resumption of intercourse Desire unchanged increased less no	(a) 79% 34% 12% 7% 18%	(b) 50%	This paper represents the first investigation on sexual functioning following treatment for gynaecological cancer that made an attempt to interview the sexual partner. Although interviewed as well, no indications of the husband's/ partner's responses are given. Authors stated that the patient's illness and her treatment provided some husbands with reasons to seek an extra-marital partner or a divorce.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Abitbol & Davenport (1974)[16] U.S.A.	Cohort of 75 women treated for cervical carcinoma stages I-II	(a) surgery-radiation therapy	15	-	- (23-68)	separate interviews by a gynaecological surgeon and radiotherapist plus pelvic examination
		(b) radiation	28	-		
		(c) surgery	32	-		
Alha & Nieminen (1974)[17] Finland	Cohort of 200 women treated for cervical cancer	(a) surgery-radiation therapy	189	-	50-59 (21-77)	interview
		(b) surgery alone	11	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results				Comment
1-5	-	Abolished or much less frequent sexual functioning	(a) 33%	(b) 79%	(c) 6%	A large number of authors cite this research as conclusively proving that radiation is more damaging to sexual function than surgery. However, the unmatched nature of the treatment groups in respect to cancer stage weakens the promulgation of Abitbol and Davenport's conclusions. Besides, the 6% sexual dysfunction among their surgical subjects is markedly lower than in hysterectomy studies. One would expect the inverse because of the compounding factors of malignancy and the more extensive procedure of a Wertheim hysterectomy.
		Lack of libido	7%	43%	6%	
		Dyspareunia	13%	39%	3%	
		Vaginal alterations	60%	78%	10%	
1-10	-	Unchanged sexual life	(a) 54%	(b) -		Unfortunately the well-reported physical symptoms were not compared to the psychosexual data.
		Diminished or no sexual activity	46%	-		
		82% attributed their sexual difficulties to psychological and climacteric symptoms.				
		Younger patients had significantly more psychological and climacteric symptoms.				
		Incidence of physical sequelae:				
		urinary difficulties	27%			
		gastro-intestinal symptoms	37%			
		diffuse abdominal pain	30%			
		swelling lower extremities	21%			

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Henning & Schulz (1975)[18] East Germany	Cohort of 201 women treated for cervical cancer stages 0 : 17% I : 55% II : 25% III : 3%	(a) surgery-radiation therapy	103	-	54	interview
		(b) radiation therapy	47	-		
		(c) surgery	51	-		
Kos (1978)[19] Jugoslavia	Cohort of 96 women treated for cervical cancer 5% CIS 91% stage I 4% stage II	(a) Schauta-Amreich	43	-	41-50	interview
		(b) Wertheim	53	-		
Beck and Nikorovicz (1980)[20] Austria	Cohort of 75 women between 1972-1977 treated for cervical cancer 75% stage I 25% stages II-III	Schauta-Amreich	5	-	41	interview
		plus radiation	6	-		
		Wertheim	29	-		
		plus radiation	35	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
6	-	Problematic sexual functioning: stage O 12% I 37% II 46% III 100% The authors noted a decreased incidence of post-treatment dyspareunia.	The decreased incidence of post-treatment dyspareunia may have been an artefact of the inclusion of subjects with stage 0 in their data. The authors found that the incidence of sexual problems sometimes arose from the partner's illness. unavailibility, or sexual dis-interest and not from factors directly related to the patient. Unfortunately, the exact prevalence of partner-related factors is not presented.
1-2	-	58% maintained more or less regular sexual relationships. 34% completely abstained because of dyspareunia and "psychic factors". Regular coitus (» once a week) pre 78% post 51% anorgasmia pre 0% post 35% less desire 20%	Data not presented in respect to the surgical procedure. No statistical analysis.
1.5-6	-	Less desire 61% dyspareunia 12% 51% anorgasmia 8% 23% The authors noticed that a reduction in sexual activity is not in line with marital dysharmony.	Differential treatment effect is not reported. The high percentage of less desire in comparison to Kos (1978) may be a reflection of cancer stage or post-surgery radiation.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Seibel, Freeman & Graves (1980)[21] U.S.A.	Cohort of 40 women treated for cervical cancer stages 0, I, II and III	(a) radiation therapy (stage I-III)	20	-	40	interview + pelvic examination
		(b) surgery (stage 0, vaginal hysterectomy with or without partial vaginectomy)	20	-		
Morf, Spinelli & Savoldelli (1980)[22] Switzerland	Cohort of 67 women treated for cervical cancer stages II and III	radiation	67	-	- (30-80)	interview

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results			Comment
≥ 1	+	None of the irradiated patients had a normal vagina: 72% had a shortened and or stenosed vaginal canal. stenosed vagina canal.			The authors conclude that "sexual function may be adversely affected by radiation therapy but in general not by surgical therapy". However, they do not independently present their data about the different stage and treatment modalities. Also, partner availability and age could explain the differences.
			(a)	(b)	
		unchanged intercourse	41%	85%	
		unchanged orgasmic frequency	22%	100%	
		Decrease in partner availability	s.	n.s.	
7-13	-	Reduced coital activity		40%	Conclusions are not justified, given the research design so many years post-treatment.
		No coital activity		34%	
		Anatomically inadequate situation for coitus		43%	

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Seibel, Freeman & Graves (1982)[23] U.S.A.	Cohort of 100 women treated for cervical cancer stages I, II, III or carcinoma in situ	(a) irradiation	43	100	51	interview
		(b) irradiation age-controlled	18		41	
		(c) non-radical surgery	44		31	
		(d) non-radical surgery age-controlled	21		36	
		(e) surgery and radiation	6		44	
		(f) radical surgery	7		53	
Bertelsen (1983)[24] Denmark	Cohort of 67 women treated for cervical cancer stages Ib-IIa	(a) surgery-radiation therapy	22	-	38	interview
		(b) radiation	45	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
≥1	+	Patients in the irradiation group had statistically significant decreases in sexual enjoyment, ability to attain orgasm, coital opportunity, frequency of intercourse and coital desire. The group with nonradical surgical procedures showed no significant change in sexual functioning after treatment. Similar results were found in both age-controlled subgroups eliminating age as the major etiological factor. 81 % of the irradiated patients had shortening and/or stenosis of the vagina. In the surgery group, the vagina was described as having mild atrophic changes in 2 women (5%).	The authors did not find a positive correlation between the changes in sexual functioning and vaginal changes. Also, no strong correlation could be detected between the loss of sexual enjoyment and the loss of self-image. When patients were asked to explain changes in coital pattern, they ascribed this change to decreased desire rather than to pain, bleeding or other causes.
(a) 1-4 (b) ≥3	-	Changed sexual functioning (a) 32% (b) 66%*) *) 60% age 40-50 23% age 30-40 17% age 20-30 Psychological factors were discussed as having contributed to the presence of sexual problems.	The author concludes that the combined treatment results in a smaller complication frequency than radiation only. The most important limitation of this study is that psychological factors, although discussed, were not measured.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Frank, Nielsen & Sjolander (1983)[25] Denmark	Cohort of 42 women treated for cervical cancer stages Ia-IIIb (81% stage Ib)	radiation-surgery	2	-	35	interview by physician alone or with a psychologist
		radiation only	40	-		
Tamburini, Filiberti, Ventafridda, Bianchi & Volterrani (1985)[26] Italy	Cohort of 98 women treated for cervical cancer	(a) radiation-surgery	61	-	<45	structured interview plus self-rating questionnaire
		(b) surgery	22	-		
		(c) radiation	15	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results				Comment
2-8	-	No change in sexual activity loss of all desire In spite of reporting decreased libido and/or dyspareunia or vaginal bleeding, 33% continued sexual activity post-therapy. No tests of significant differences pre- and post-treatment were reported. Post-treatment: 90% had slight vaginal changes, 67% significant climacteric symptoms, 64% benefited from oestrogenic preparations, although no change in sexual function was associated with hormonal use.		27% 39%		The authors concluded that physical changes alone did not explain the perceived changes in sexual function and that post-therapy changes were also related to psychological factors, such as anxiety.
	+	Deterioration in sexuality Worsening in emotional relationship Disruption in work activity Differences in the area of sexuality are not significant.	(a) 46% 36% 53%	(b) 35% 41% 41%	(c) 33% 27% 20%	The authors "feel" that in patients subjected to hysterectomy, psychological factors play a role of equal, if not more importance, than the iatrogenic anatomical damage, as a cause for sexual damage, while in patients given radiotherapy the etiology of the sexual damage is mainly linked to anatomical damage.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Lasnik & Tatra (1986)[27] Austria	Cohort of 57 women treated for cervical cancer stages I-III	radiation therapy	57	100	- (30-65)	interview
Walcher, Ralph, Lahousen, Scheer, Tamussino & Rollett (1988)[28] Austria	Cohort of 87 women treated for cervical cancer	(a) Wertheim-Meigs (b) Schauta-Amreich	76 11	69	- (29-73)	interview

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results		Comment
≥1.5	-	No more intercourse Reduced coital frequency Dyspareunia Short or narrow vagina Reduced libido Coital anorgasmy before Coital anorgasmy afterwards	16% 68% 50% 21% 58% 14% 52%	The authors observed that the sexual life was not disturbed in those women who had been well-informed about the consequences of the irradiation and who had resumed intercourse soon after the therapy.
1-15	-	Reduced libido Reduced coital frequency 20% felt they had been adequately informed of possible sexual consequences of the treatment.	58% 62%	Methodological deficits in this study do not justify any conclusion concerning sexual rehabilitation of cervical cancer patients. Additional treatment effects have been ignored.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Endometrial cancer						
Jenkins (1988)[29] U.S.A.	Cohort of 27 women treated for endometrial (24) and cervical cancer (3)	surgery and radiation therapy	20	-	- (21-75)	self-report questionnaire
Vulvar cancer						
Disaia, Creasman & Rich (1979)[30] U.S.A.	Cohort of 20 women treated for vulvar cancer	wide excision of the lesion	18	-	46 (median)	interview
	micro-invasive disease	radical vulvectomy	2	-	(34-58)	

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results		Comment
0.5-5	-	The respondents, as a group, showed a significant decrease in the actual frequency of intercourse and orgasm and in their feelings of desire and enjoyment after treatment.		This is the one and only study focussing in particular on patients with endometrial cancer. The author's conclusion that the data suggest that endometrial cancer patients have sexual functioning problems similar to patients with cervical cancer is obvious but remains sheer speculation. Apart from methodological shortcomings he did not make direct comparisons. The data on the absence of sexual counseling confirm earlier reports on this issue.
		Dyspareunia	76%	
		Vaginal dryness	60%	
		Narrowed or shortened vagina	53%	
		Received no information on sexual functioning	95%	
		The professional needs to initiate sexual discussion with patients at risk	88%	
0.5-6	-	Adequate sexual functioning had been preserved completely in the 18 patients who underwent wide local excision, in contrast to two patients who underwent radical vulvectomy because of the peri-clitoral location of the micro-invasive disease. All the women except the radical vulvectomy patients continued to be orgasmic during sexual activity. The women with radical vulvectomy reported a significant change in sexual response.		Although the number of women with radical vulvectomy was small, the study demonstrates that the magnitude of surgical intervention correlates with the sexual outcome.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Choo (1982)[31] U.S.A.	Cohort of 6 women treated for vulvar cancer	radical vulvectomy	17	-	28 (18-35)	interview
Moth, Andreasson, Jensen & Bock (1983)[32] Denmark	Cohort of 15 women treated between 1974 and 1980 for vulvar cancer and their partner	radical or simple vulvectomy	15	-	49 (32-60)	interview + partner

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
up to 29	-	All but one patient reported no significant decrease in libido. Three women reported no difference in orgasmic feeling during sexual intercourse. Two had diminished sensation and in one patient it was absent. Surgery had no effect on the sexual attitudes of their partner. One patient complained of dyspareunia.	The small number of women interviewed retrospectively so many years after the surgery, does not justify any conclusion concerning sexual rehabilitation in radical vulvectomy patients.
1-8	-	50% stopped sexual activity Main reason: dyspareunia 66% reduced libido reduced sexual arousal orgasmic dysfunction and/or dyspareunia 84% changes in mood 91% tiredness 50% changes in feelings about being a woman 35% less acceptance of one's own body 64% lowered self-confidence 57% preoccupation with health Partners: 7/8 reported depression 4/9 less acceptance of the woman's body 4/8 preoccupation with health None of the partners developed sexual dysfunctions.	This study represents the first research into sexual functioning following treatment for gynaecological cancer that systematically assessed the partners's sexual functioning and considered the intervention of the health care provider. Most of the women had received some information about sexual functioning from their health care providers. Only one out of the 9 partners mentioned that the informations was "barely adequate".

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Andersen & Hacker (1983)[33] U.S.A.	Cohort of 15 women treated for vulvar cancer (n=10) or CIS (n=5)	radical vulvectomy	7	-	55 (30-70)	semi-structured interview and psychological test battery
		total vulvectomy	5	-		
		partial vulvectomy	3	-		
Stellman, Goodwin, Robinson, Dansak& Hilgers (1984)[34] U.S.A.	Cohort of 14 women treated for vulvar cancer and 14 women treated for endometrial cancer stage II	(a) vulvectomy	9	64	53	self-report questionnaires
		(b)hysterectomy and radiation	7	50		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
1/4-9	+	Mild distress. Reasonable levels of and satisfaction with free-time and social activities. Mild levels of marital distress. Major disruption of sexual functioning and body-image despite the fact that intercourse remained possible. Levels of sexual arousal at the eight percentile and body-image at the fourth percentile. Penile penetration was not felt because of persistent numbness. The loss or maintenance of orgasm was reported by those with and those without clitoral excision.	Although these results are limited by the absence of pre-treatment observations, repeated assessment and comparison groups, they provide the first substantive look at the post-treatment life circumstances of these patients. The data indicate that these patients attempted to maintain a sexual life despite major physical losses and substantial emotional disruption.
± 3	-	(a) (b) Depressed 67% 0% Anxious 67% 14% Hostile 34% 14% No current sexual experiences 78% 29% Unsatisfied with this 56% 29% No intercourse 100% 29% Problems with body image 56% 43% Currently satisfied sexually 22% 57%	The authors recognized the fact that the small number of patients precludes any certainty in generalization. They recognized that women undergoing vulvectomy are unable to learn about the effects of surgery and that the husband or sexual partner should be involved by the treatment team from the time of diagnoses, through surgery and postoperatively.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Weijmar Schultz, Wijma, Van de Wiel, Bouma, Janssens (1986)[35] The Netherlands	Cohort of 10 women treated for vulvar cancer	radical vulvectomy	10	83	54 (27-69)	self-report questionnaire
Andreasson, Moth, Jensen & Bock (1986)[36] Denmark	Cohort of 25 women treated between 1971 and 1981 for vulvar cancer (n=15), precancrosis vulvae (n=9), lichen sclerosis et atrophicus (n=1)	radical vulvectomy simple vulvectomy	15 10	- -	46 (27-69)	interview plus partner
Tamburini, Filiberti, Ventafridda & De Palo, (1986)[37] Italy	Cohort of 21 women treated for vulvar cancer	radical vulvectomy	21	-	55 (48-60)	structured interview plus self-rating questionnaire

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
±2 1-6	-	Despite many problems, 8 out of the 10 couples accomplished complete or partial sexual rehabilitation. It is demonstrated that sufficient information, sufficient coping and sufficient communication does not guarantee complete sexual rehabilitation. One of the women conceived after the radical vulvectomy and had an uncomplicated vaginal delivery.	There is a remarkable difference in outcome on sexual rehabilitation between this study and the existing literature. The authors suggested that motivation for sexual expression and mutual affection might be more important for sexual rehabilitation than any physical restriction imposed by the surgery.
1-11	-	More than half of the women had both sexual dysfunction and psychological problems. Their partners had no sexual dysfunction but almost half had psychological problems. 24% of the women were able to achieve orgasm in spite of the extensive surgery. Dyspareunia was a major complaint. The couples that resumed sexual relationship started an average of 10 weeks after the operation.	This study confirms the former results of the same investigators. Again, the importance of sexual counselling is emphasized, both before and after surgery, which also involves the partner. as well.
0.5-5	-	Analyses indicated a decrease in emotional adjustment, 41% regarding work and regarding sexual activity. High values for the 3 "neurotic" scales (hysteria, hypochondria, depression) were found.	In comparison with a similar study on patients treated for cervical cancer (Tamburini et.al, 1984) the authors found a significant increase in psychological and sexual discomfort in vulvectomy patients.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Andersen, Turnquist, LaPolla & Turner (1988)[38] U.S.A.	Cohort of 42 women treated between 1975 and 1983 for vulvar cancer in situ plus 42 women seeking routine gynaecological care	laser or chemo-therapy	6	88	50 (31-81)	structured assessment interviews and psychological test battery
		wide local excision	26			
		simple/total vulvectomy	9			
		radical vulvectomy	1			
		healthy women	42			

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
1-10	+	Sexual behaviour patterns appeared to be maintained, as was the desire phase of the sexual response cycle. There was specific disruption of the phases of excitement and resolution (residual tension, general sexual dissatisfaction) and, to a lesser extent, orgasm. In addition, a two to threefold increase in the frequency of sexual dysfunction. 30% of the sample was sexually inactive at follow-up. More extensive treatment correlated significantly with disruption of the desire and resolution phases of the sexual response cycle. Sixty to 84% of the patients received no information regarding sexual outcome.	Although limited by the lack of pretreatment observations, the study indicates that surgical vulvar treatment may result in a change in responsiveness and in the incidence of sexual dysfunction. The magnitude of surgical intervention correlated with the sexual outcome. Sexual activity was maintained and women did not lose their desire for sexual activity, despite the excitement and orgasm difficulties. Marital data indicate satisfactory relationships.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Radical pelvic surgery						
Brown, Haddox, Posada & Rubio (1972)[39] U.S.A.	Cohort of 15 women treated for cervical cancer (n=14) and cancer of the vulva (n=1)	(a) total pelvic exenteration	13	28	44 (35-59)	interview and psychological test battery
		(b) posterior exenteration and radical vulvectomy	1			
		(c) anterior exenteration	1			
Morley, Lindenauer & Youngs (1973)[40] U.S.A.	Cohort of 15 women who underwent surgery for pelvic genital cancer with creation of a neovagina	exenteration with vaginal reconstruction	13	100	(33-58)	interview
Sewell and Edwards (1980)[41] U.S.A.	Cohort of 46 women who underwent surgery for pelvic genital cancer	Wertheim	16	-	40	psychological tests (self-esteem, social adjustment, locus of control, relationship and sexual adjustment panel, a body-image scale). Also pretreatment ratings
		radical vulvectomy	15	-	55	
		exenteration	15	-	54	

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results		Comment
± 7	-	Sexual activity usually enjoyed in the past	87%	Two findings in this study not previously reported: phantomization of the vagina and erotization of the colostomy stoma in cancer patients.
2-13		Postoperative sexuality		
		Dreams with sexual content	27%	
		Acknowledges sexual interest	27%	
		Acknowledges auto-erotic practices	27%	
		Despite the stress to which these patients were subjected, especially related to desexualization and colostomy, overall social and psychological adjustment was favourable.		
1-7	-	Satisfactory sexual relationship	100%	The authors state "that one should not attempt to equate the patients's satisfaction with a surgically constructed vagina, in terms of sexual response, with that of a patient with a normal vagina and no pelvic carcinoma".
		No dyspareunia		
		Two women reported orgasmic response in spite of clitoridectomy.		
≥1/2	+	Excellent adjustments in terms of general well-being, self-esteem and social readjustment. Significant changes in body-image, sexuality and interpersonal relationships: exenteration ≥ radical vulvectomy ≥ Wertheim. Post-hoc analysis suggested the older women with more lengthy relationships to have less problems than younger		This study clearly demonstrated personality and social adjustment measures to be related to each other but not to body-image or sexual functioning. The three treatment modalities have in common: the potential to severely limit the sexual response cycle.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Vera (1981)[42] U.S.A.	Cohort of 19 women treated for recurrent cervical carcinoma (18) or recurrent vulvovaginal carcinoma	exenteration	19	92	51 (38-62)	structured interview
Magrina & Masterson (1981)[43] U.S.A.	Cohort of 10 women treated between 1974 and 1978 for CIS (2), recurrent CIS (3), adeno-carcinoma in situ (1) and squamous cell carcinoma in situ of the cervix (4)	radical pelvic surgery with vaginal recon-struction	10	-	44 (24-64)	case-record

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
1/2-9	-	Women appeared well-adjusted and subjectively appraised their quality of life as good in spite of poor occupational recovery, a decrease in social activities and a significant loss of sexual life. Three of the women (20%) who had been sexually active prior to surgery, continued to have some activity postsurgery. Only one found it satisfying for her and her partner.	Referring to Lamont et.al (1978) authors do not advocate that sexual re-education be available, but considering the special situation of individual patients so as not to create unrealistic expectations.
concomitant	-	For six women functional results (=intercourse) were satisfactory, for one woman despite unsatisfactory anatomical results. For two women results were unsatisfactory despite adequate anatomical situation.	In this article authors clearly focus on functional anatomical aspects of vaginal reconstruction. This is clearly reflected in the results. Their advice to consider vaginal reconstruction in motivated women only, was not unexpected. They ignored the contribution of the partner.

Table I Sexual functioning after gynaecological cancer treatment: post-treatment studies on

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Andersen & Hacker (1983)[44] U.S.A.	Cohort of 15 women treated for cervical cancer stages Ib, IIb, IIIb (n=14) and vaginal cancer (n=1)	total exenteration	9	-	54	semi-structured interview and psychological test battery
		total exenteration with subsequent colostomy closure	3	-		
		total exenteration with vulvectomy	1	-		
		Anterior exenteration	2	-		

"gynaecological malignancy", cervical cancer, endometrial cancer and vulvar cancer.

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
5.5	+	Although mildly distresses and depressed, the women reported active and satisfactory levels of social and free-time activities. Sexual functioning continued to the area of greatest disruption for these patients and, as a group, they resembled severely dysfunctional healthy women. Disruption of sexuality included reduction in the frequency of sexual activity, low sexual arousal and satisfaction and disruption of sexual confidence and body-image. Analyses of variance indicated significant differences in the area of sexual functioning between the sexually active and non-active patients and the patients with a neovagina and those with no vaginal capacity, but no difference regarding psychological or social adjustment.	The complete loss of sexual activity in some patients and the significant disruption of this function for virtually all patients, was a clear outcome. Incidental reports from women led the investigators to believe that reconstructive surgery may have a positive impact on body-image. Objective evidence indicated no significant enhancement of body-image. More observations are needed. The authors stated that "sexual difficulties appear to be more or less distressing to a patient depending on the availability of a sexual partner and the patient's own desire for the continuation of her sexual life.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Radical pelvic surgery						
Kilkku, Grönroos & Punnonen (1982)[45] Finland	Cohort of 64 women treated for cervical dysplasia and CIS	conization	64	-	27 (17-52)	interview plus medical examination
Vincent, C.E., Vincent, B., Frank, Greiss & Linton (1975)[46] U.S.A.	Cohort of 50 women treated for cervical cancer stages I-II groups were matched for age, socio-economic status, parity and stage of disease	(a)surgical treatment (b)radiation	25 25	98	41 (25-61)	interview
Adelusi (1980)[47] U.S.A.	Cohort of 101 women treated for cervical cancer stages I-III	(a)stage I, IIa or IIb, treated with therapeutic doses of radiotherapy (two insertions of 137Cs)	62	-	45	interview
		(b)stage III treated with palliative doses of radio-therapy (one insertion of 137 Cs)	39	-		

pre-post treatment studies

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment 6 weeks, 6 months, 12 months post-treatment	+	No significant difference pre-post-treatment on libido, orgasmic and coital frequency. Statistically significant decrease dysmenorrhea and dyspareunia.	The author stresses the fact that he himself interviewed and examined the women each time, thus making the results more reliable (sic).
prior to treatment during treatment 6 months post-treatment 12 months post-treatment	-	Few differences in pretreatment and posttreatment sexual functioning (desire for coitus, frequency of intercourse) were observed between the treatment groups. Only a diffference in changes in coital positions! 70% of the subjects received no information about sexual functioning from their oncologist. 67% would have liked more information, 79% were awaiting the physician's initiation of a discussion about sexual functioning.	Unlike some other studies, Vincent's research design most probably had a positive intervention effect, as sexual functioning was discussed with the patient by the same interviewer prior to and after the treatment.
prior to treatment between 12 and 18 months postradiation	-	Abstaining from intercourse: I 29%, (a) IIa 62%, IIb 69%, (b) 97% Within group (b) 83% complained of irregular vaginal bleeding. Within group (a) of those who reported decreased intercourse, 90% complained of dyspareunia and concurrent fears of postcoital bleeding and cancer recurrence.	The inverse relationship between stage of disease and sexual activity level, appears to substantiate the hypothesis that sexual functioning is partially related to the extent of disease and the severity of the subsequent treatment. The author attributed the dyspareunia to the higher radiation dose and to patient fears: two internal implants signal more serious disease.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Hansen (1981)[48] Denmark	Cohort of 211 women treated for cervical cancer stages Ib-IIa	(a)surgery-radiation therapy	111	-	(a) 43 (b) 59	interview
		(b)radiation	70	-	(c) 45	
		(c)surgery	30	-		
Poulsen, Kristensen& Hansen (1983)[49] Denmark	Cohort of 27 women treated for cervical cancer stages Ib-IIa	(a)surgery-radiation therapy	17	-	45	interview
		(b) surgery	10	-		
Schover, Fife & Gershenson (1989)[50] U.S.A.	Cohort of 61 women treated for cervical cancer stage Ia, Ib and IIa	(a)radical hysterectomy	26	80	38 (23-60)	structured interview questionnaires and Pelvic Exam Rating Form
		(b)radiotherapy with surgery	12			
		(c)radiotherapy without surgery	23			

pre-post treatment studies

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment post-treatment period not mentioned	-	Unchanged sexual functioning (a) 53% (b) - (c) 53% Impaired or dysfunctional sexual status 11% - 11% In the combined treatment group no radiation-induced vaginal changes were observed.	Based on these results, the author states, "Sexual function will not be impaired by surgery or a combination of radium and surgery". However, given the disparity of age and general physical health status between his treatment groups and his failure to interview the irradiated subjects, Hansen's conclusion seems premature.
prior to treatment 14-28 months post-treatment	-	Changed sexual functioning (decreased coital or orgasm frequency and/or libidinal levels) occurred in 40%. Data were not reported according to treatment group.	These findings are consistent with the earlier study by Hansen (1981).
at the onset of treatment 6 and 12 months post-treatment	+	Irrespective of treatment modality: no change in - sexual satisfaction - orgasmic capacity - frequency of masturbation, but a significant decrease in - frequency of sexual activity - range of sexual practices. Within one year, however, the radiotherapy group developed dyspareunia and had more problems with sexual desire and arousal than the surgery-alone group. These women were less likely to resume several daily life activities as well. Cancer treatment modality was not related to marital happiness or stability, however.	The most important finding in this study was the delayed impact of radiotherapy on women's sexual functioning. This difference between surgery and radiotherapy groups was not found by Vincent et.al (1975). The latter groups were fairly similar because of random assignment to cancer therapy. A control group of women who underwent gynaecological surgery for benign disease was not available in this investigation.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (rang	Data collection
Andersen, Andersen & deProsse (1989)[51a/b] U.S.A.	Cohort of 47 women treated for early stage ovarian cancer (5), cervical cancer (23) and endometrial cancer (9)	(a) radical hysterectomy	23	85-95	42	structured interview and self-report questionnaires assessing sexuality and other psychological and physical data
		(b) radiotherapy with surgery	11		(25-65)	
		(c) radiotherapy without surgery	13			
		(d) simple hysterectomy for benign disease	18			
		(e) healthy women	57			

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment and 4, 8 and 12 months post-treatment	+	Global sexual behaviour disruption did not occur. Frequency of intercourse declined in women treated for disease, whether malignant or benign, but there were no significant changes on this point in comparison with healthy women at the 8 and 12-month assessments. Changes in the sexual response cycle occured, in particular diminution of sexual excitement which was more severe and distressing for women with cancer. The authors attributed this to significant coital and postcoital pain, premature menopause, treatment side effects, or a combination. The authors stressed the absence of any change in the measure of sexual anxiety, indicating that the arousal problems in the women with disease were not anxiety-based. There was no evidence of a higher incidence of relationship dissolution or poorer marital adjustment; however, 30% of the women treated for disease reported that their sexual partners may have had some difficulty in reaching orgasm after the subject's treatment. This difficulty with ejaculation was concordant with the women's patterns of sexual distress.	In this thorough (but limited) prospective longitudinal design, sexual functioning was operationalized in three dimensions: sexual behaviour, sexual response and the diagnosis of sexual dysfunction. A comparison was made between healthy women and women treated for benign disease. The data suggested an instrumental role for cancer and cancer treatments in the etiology of this aspect of life disruption in women. Based on their results, the authors provided directions for the design of interventions for women with cancer.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Lamont, De Petrillo & Sargeant (1978)[52] Canada	Cohort of 12 women treated for "pelvic" malignancy"	exenterative surgery	12	-	-	interview plus counseling (team-approach)
		creation of neovagina	10	-		
Dempsey, Buchsbaum& Morrison (1975)[53] U.S.A.	Cohort of 16 women treated for recurrent cervical carcinoma (12) or persistent cervical carcinoma (11) or vulvo-vaginal carcinoma (3)	exenteration	16	-	51 (35-60)	structured interview
Harris, Good & Pollack (1982)[54] U.S.A.	Cohort of 96 women treated for cancer of the vulva, vagina, cervix, uterus, tubes and ovaries	(a) before symptoms or diagnosis	96	-	52	63-item sexual behaviour questionnaire
		(b) after symptoms or diagnosis				

pre-post treatment studies

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment 6 weeks to 12 months post-treatment	-	Seven out of the eigt women with good sexual attitudes and adjustments preoperatively, resumed sexual activity and had good postoperative adjustment. Six out of the seven were orgasmic within six months after surgery. One male complained of difficulty with erection and ejaculation control in the early post-operative period related to his anxiety about resuming the sexual relationship.	The study revealed that despite the loss of sexually responsive tissue in the pelvis, exenteration does not obliterate orgasmic capacity. But more love-play and stimulation were necessary to enable the women to achieve the same degree of sexual tension. To maintain vaginal capacity in a previously irradiated pelvis, ongoing care and dilatation is needed. The most important factor in total sexual relationship rehabilitation is partner education, his acceptance and interest.
pre-operatively during the early postoperative period during subsequent follow-up visits	-	Postoperative adjustment was satisfactory to excellent for the surviving women (87.5%) except for sexual functioning. Only three of the ten sexually active women preoperatively had sexual activity postoperatively. These were the women in whom the external genitalia had not been excised.	In this study "sexual activity" is defined as the frequency of intercourse and orgasmic capacity. None of the women who lost their ability for sexual intercourse regarded this as a significant burden upon her or her husband. The partners were not questioned.
on admission prior to onset of treatment	-	General satisfaction with sex life (a) 85% (b) 48% Cessation of coitus (b) 50% Reduced frequency (b) 30% Satisfied with coital frequency (a) 80% (b) 48% Experienced orgasm frequently (a) 58% (b) 15% Discussed sex life easily with partner (a) 55% (b) 33%	The study indicated a decrease in sexual activity and satisfaction in women with newly diagnosed gynaecological cancer but is of limited value because no differentiation was made between the different kinds of cancer and the treatment and no statistical analysis was performed. The importance of the partner regarding sexual rehabilitation was recognized.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Andersen, Lachenbruch, Anderson & DeProsse (1986)[55] U.S.A.	Cohort of 41 women with early stage cervical or endometrial cancer and a matched group of healthy women	(a) recently diagnosed as having cervical or endometrial cancer	41	96	-	structured interview and self-report questionnaires assessing
		(b) healthy women	41	85		
Cain, Kohorn, Quinlan, Schwartz, Latimer & Rogers (1983)[56] U.S.A.	Cohort of 60 women newly diagnosed with cervical, uterine and ovarian malignancies	(a) gynaecological cancer patients	60	80	Model age 61-70	structured interview and self-report questionnaires
		(b) women from psychiatric clinics	40			
		(c) normal population	272			

pre-post treatment studies

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment women were asked to report sexual responses immediately prior to any recent symptomatic period and sexual responses during the recent symptomatic period	+	Prior to the onset of cancer signs/symptoms, the gynaecological cancer patients reported similar patterns of sexual activity and responsiveness to the healthy sample. With the appearance of disease signs, however, the gynaecological cancer patients reported experiencing significant sexual dysfunction symptoms.	This study showed that a patient's prediagnosis-sexual-functioning may be influenced by the onset of cancer signs and symptoms. One should realize that the information about sexual functioning prior to the onset of cancer signs and symptoms in this study was retrospective. It might be influenced by the confrontation with cancer diagnosis without any signs and symptoms as well.
within one month of diagnosis	+	Findings show that within one month of diagnosis women experienced mild to moderate symptoms of depression and anxiety, as well as impairment of vocational, domestic and sexual functioning. Although the overall marital relationship with spouse or partner continued to be satisfactory, sexual intimacy changed dramatically. All 29 women with a satisfying sexual relationship before the disease, ceased to have sexual intercourse after diagnosis.	The authors stated that many of the impairments, such as the ability to work, perform domestic chores, or function sexually, resulted directly from the the patient's psychosocial reaction to the cancer and treatment. However, within one month of diagnosis this same statement applied to physician factors or physical factors too: they were told to abstain following surgery, or they believed sexual intercourse would exacerbate vaginal bleeding or vaginal discharge".

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Capone, Good, Westie & Jacobson (1980)[57] U.S.A.	Cohort of 79 women treated for gynaecological malignancies	(a) counseling during hospitalization	56	-	average age 40	psychological tests and semi-structured interview
		(b) no counseling	41	-		
Weijmar Schultz, Van de Wiel, Bouma, Janssens and Littlewood (1990)[58] The Netherlands	Cohort of 10 women treated for vulvar cancer	(a) radical	10	77	49 (37-60)	structured interview and self-report questionnaires assessing sexuality and physical variables
		(b) healthy women	60			

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
prior to treatment and 3, 6 and 12 months post-treatment	+	No or less intercourse (a) (b) at 3 months: 41% 80% at 6 months: 29% 80% at 12 months: 16% 57% This differences were significant. Psychological scales revealed no significant differences between the two groups.	This study demonstrated that 1. clinical intervention in the sexual rehabilitation of patients treated for gynaecological malignancy is of measurable value and 2. sexual functioning after gynaecological cancer treatment may be affected by health-care-provider intervention variables.
prior to treatment and 6, 12 and 24 months post-treatment	+	Within one year, all women who were sexually active before the treatment had resumed their sexual activities. At the six month assessment, an increase in in relational sexual dissatisfaction was observed. Over the remaining observation period the women's satisfaction with sexual interaction with the partner was not found to be different from their pre-treatment satisfaction and not different from the satisfaction in the control group, in spite of the physical damage and persisting poor perception of genital symptoms of sexual arousal during love-making.	The authors concluded that satisfaction with sexual interaction with the partner under these circumstances appears to be more an expression of satisfaction with the intimate aspects of the sexual relationship than of satisfaction with the physiological aspects of the sexual relationship.

Table II Sexual functioning after gynaecological cancer treatment:

Author(s)	Sample	Group(s)	N	Resp. %	Average age (range)	Data collection
Van de Wiel, Weijmar Schultz, Hallensleben, questionnaires Thurkow, Bouma, Verhoeven (1990)[59] The Netherlands	Cohort of 7 women treated for vulvar cancer	(a) radical vulvectomy	7	50	49	interview and self-report
		(b) healthy women	24		(37-60)	
Van de Wiel, Weijmar Schultz, Wouda and Bouma (1990)[60] The Netherlands	Cohort of 16 partners of women treated for gynaecological cancer		16	68	51 (33-70)	semi-structured interview

Moment of assessment post-treatment in years	Statistical analysis	Results	Comment
12 months post-treatment	+	According to the participant's point of view, rather dramatic changes in sexual life occured because of the cancer and the treatment. However, if compared with the data from an age-matched control group, far less dramatic differences could be traced on on the main aspects of sexual functioning, i.e. sexual satisfaction, sexual behaviour and sexual motivation. Only significant differences in experienced sexual arousal and orgasm were observed.	The authors hypothesize that sexual rehabilitation itself is determined at a higher level by a more general striving for balance in the relationship. Interventions to prevent or reduce sexual problems after gynaecological cancer treatment should not only be directed towards the patient but also towards the partner.
12 months	-	It appeared that many men experienced the process of providing support as a stressful process and had serious doubts about the support provided. The female partners had extensive sexual problems, which could not be solved adequately.	The authors stated that because of the limited generalizability of the results of the study, only some cautious conclusions can be drawn. They hypothesized that the disease and the treatment also poses a crisis for the partner, which leads to a regression towards a more rigid, male stereotype way of coping. Results make clear that attention should not only be paid to the patient during treatment, but also to her partner and to their communication patterns.

PART II

AN EMPIRICAL APPROACH

Chapter 5

Methods and Materials

We had been warned. On a Post Graduate Course on Psycho-Oncology in New York, September 1984, Yates[1] supplied the audience with the following rule of thumb: "Divide the estimated number of participants in psycho-social cancer research by ten and this will provide you with the final number of participants". The original plan of our investigation under gynaecological cancer patients comprised an estimation of two hundred participants. Our definitive experimental patient population comprised of thirty-six participants, with all its consequences.

The original plan, a multivariate modelwise evaluation of the data, had to be left and a more descriptive plan of investigation had to be introduced.

Based on the literature (see Chapter 4) the following central themes of description were chosen:

1. the evolvement of sexual functioning in time, starting from before the onset of the disease until a specific moment in time, i.e. when no more changes induced by the disease or treatment are to be expected;
2. a comparison of the cancer patient population with a group of non-oncological gynaecological patients;
3. a comparison of the cancer patient population with a control group of gynaecologically healthy women.

To answer the question "How do internal and external factors (co)determine sexual functioning before and after gynaecological cancer treatment?" a within group correlational design was used.

Hypotheses and their operationalizations are elaborately discussed in the introductions and method of the various articles (Chapter 6). Therefore in this chapter only a general outline of method and materials, used in these studies, will be provided. First the three different designs will be discussed, followed by the (sub) groups of participating subjects. Then the independent and dependent variables, the covariables and the confounding variables will be discussed. Each discussion is followed by the concrete operationalization of the specific variables in terms of questionnaires, checklists, interviews or psychophysiological measurement.

5.1 Design

In order to answer the diverse research questions in this study three types of designs were used, which will be discussed here briefly:

- a longitudinal design
- a between groups design
- a correlational design.

5.1.1 A longitudinal design

In order to study the evolvement of sexual functioning in time a "limited" prospective longitudinal design was used. The prospective design is "limited" because the initial assessment of the patient groups occurred on admission. A real pre-post design demands an initial assessment before cancer signs and symptoms. This is virtually impossible because random assignment to "cancer" and "noncancer" conditions is not possible, neither by inducing cancer in the experimental population, nor by selecting a sample of the healthy population and wait untill some of them become gynaecological cancer patients.

Retrospective evaluation of sexual functioning before the onset of cancer signs and symptoms was carried out at the first assessment, i.e. during admission for cancer diagnosis and treatment. This procedure of course holds some risks too. For example, it is possible or even to be expected, that after treatment the patients idealize the situation before treatment. In order to control for this kind of biasses a "between groups design" (see 5.1.2.) was added to the study.

The longitudinal aspect included three posttreatment assessments at 6-, 12-, and 24-months. These moments of assessment were chosen because studies of patients with carcinoma of the cervix[2] and of breast cancer patients[3-4] have indicated that significant disruption of sexual functioning appeared within the first year post treatment. Additional assessments at 12 and 24 months posttreatment were to determine if any early sexual disruption would resolve and/or if new sexual problems would occur late. Longitudinal data of this type make it possible to determine the optimal point in time in case intervention is desirable.

5.1.2 A between groups design

To be able to interpret the changes in sexual functioning after gynaecological cancer treatment, the scores on relevant variables of the women in the experimental condition should be compared with the scores of other patient groups and non-patient groups. Therefore two control groups were added to the study: an age-matched group of women with recently diagnosed benign gynaecological disease, to be treated with a "simple hysterectomy", and an age matched group of gynaecologically healthy women.

The simple hysterectomy group was chosen because it provides a non-cancer estimate of disruption due to gynaecological disease and treatment. It is known that emotional distress and/or sexual difficulties may accompany gynaecological surgery for benign disease.[5]

The non-patient control group was chosen because it provides information on sexual functioning of a similar group of women if the disease would not have occurred.

To control for the testing effect, i.e. variability produced by the measurement procedures, a fourth group was added to the design: gynaecological oncology patients who were not assessed four times but only once, 12 months post treatment.

5.1.3 A correlational design

Based on the review of the literature (Chapter 4) and on our own model of sexual functioning a number of variables were assessed, potentially playing a major role in sexual functioning before and after gynaecological cancer treatment. Up till now, no empirical evidence exists on these hypothesized relations. By correlating these variables with the core variables of our model, it should be possible to measure their influence.

5.2 Subjects

Before subjects were recruited, women were excluded from participation according to the following criteria:

- age < 16 or > 70 years;
- history of psychiatric or somatic disorder that might interfere with the sexual relationship.

No restrictions were made about sexual preference or marital status. Partners were invited to participate in the study. The voluntary nature of participation was stressed and it was made explicitly clear that it would be possible to withdraw from the research programme at any time. Therefore no pressure was set on those who immediately refused to participate nor on those who ended their participation during the 24 months of the study, although this latter procedure made analysis of drop-outs impossible.

Details about the demographical and medical status of all participating gynaecological cancer patients and their partners is given in the various articles.

Vulvar cancer. A consecutive group of thirteen women and their partners were invited to participate in the research project. Three couples did not feel capable to participate because of emotional reasons. Response rate: 77%.

Cervical cancer. Seventy-two women and their partners were asked to participate. Eighteen couples did not feel capable to participate. Response rate: 75%.

The partners. Although most women were married, for practical reasons only twenty-four partners were asked to participate. Eight of them refused. Response rate: 67%.

Detailed information on the participating partners is provided in chapter 6.

Testing control population For this population the same in- and exclusion criteria were used as for the gynaecological cancer group but the testing control population was assessed only once, 12 months post treatment. Ten women participated in this group.

Gynaecologically healthy women For this group the same exclusion criteria were used. Furthermore, women who had undergone major gynaecological surgery in the past were excluded from the study. Most women were regular visitors of the hospital for contraception and some others were contacted by advertisement.

Simple hysterectomy control population For their recruitment the same exclusion criteria and procedures were followed as with the gynaecological cancer patients. 29 patients were asked to participate of whom 7 refused. The response rate was 76%.

5.3 Independent and dependent variables, covariables and confounding variables

5.3.1 Independent variables

The main independent variable was the type of gynaecological cancer: cancer of the cervix and cancer of the vulva. A distinction was made between the method of treatment i.c. surgery, radiotherapy or combined treatment (see chapter 3).

Operationalization:

- Medical Checklist.

5.3.2 Dependent variables

In the preceding chapters it has been discussed that measuring sexual functioning by means of a single behavioural measure (e.g. intercourse frequency), an indication of responsiveness (e.g. presence or absence of orgasm), or an estimation of global satisfaction is not a valid way to conceptualize sexual functioning. Therefore we chose for a multidimensional approach, in which motivational, behavioural and emotional variables were used as defined in terms of the Social Learning Theory of Rotter.[6] Besides, sexual arousability was measured in terms of the sexual response as defined by Masters & Johnson.[7] Aside from the validity perspective and the methodological importance to use multiple convergent measures, the clinical utility of this strategy is that it provides information for designing interventions to cure or prevent sexual problems after treatment.

To obtain reliable as well as valid data, the decision was made to use self-report questionnaires as the main source of data gathering.

Nearly all dependent variables were operationalized for theoretical and practical reasons by means of the Intimate Bodily Contact Scale (IBCS) of Vennix[8]. Theoretically because this scale is also based on Rotter's theory on social learning and practically because in the Netherlands it is the only well investigated and psychometrically funded scale available. The IBCS is an extensive self-report questionnaire, which contains 22 subscales covering various detailed aspects of sexual functioning. The subscales are standardized for heterosexual Dutch men and women separately and the internal consistency is generally high. For a more detailed description of the concept and development of this scale we refer to Vennix.[8-9]

Although most variables could be operationalized by means of the IBCS, a number of variables could not. For these remaining variables special scales were designed, marked with an asterisk, or existing other scales were adapted. For these scales norms for the female population as well as the reliability scores were developed during this study. A detailed description of the newly developed questionnaires is provided in chapter 6.

As a reminder, here the core variables of sexual functioning after gynaecological cancer treatment will be briefly discussed once again in the light of the earlier described theories on sexual functioning.

Sexual motivation and overt sexual behaviour; In terms of Rotter's theory on social learning, the subject's experience with sexual motivation and overt sexual behaviour can be "ideal" and can be "real".

Ideal experiences meet the subject's aim in sex matters. These aims can be subdivided into two categories: 1. appreciation for sexual arousal and 2. appreciation for intimacy. Sexual arousal includes sexual arousal-inducing-behaviour as well. Intimacy includes intimacy-inducing-behaviour as well. In this way four different aspects of sexual motivation are distinguished:

- appreciation of sexual arousal-inducing-behaviour
- appreciation of intimacy-inducing-behaviour
- appreciation of sexual arousal
- appreciation of intimacy

Real experiences are the actual behavioural and emotional results of the sexual interaction. Again four different variables can be identified:

- freqency of sexual arousal-inducing-behaviour
- frequency of intimacy-inducing-behaviour
- frequency of sexual arousal
- frequency of intimacy

Operationalization:

Ideal experiences:

- appreciation of sexual arousal	IBCS-8
- appreciation of intimacy	IBCS-7
- appreciation of sexual arousal-inducing-behaviour	IBCS-22
- appreciation of initimacy-inducing-behaviour	IBCS-21

Real experiences:

- frequency of sexual arousal	IBCS-2
- frequency of intimacy	IBCS-1
- freqency of sexual arousal-inducing-behaviour	IBCS-20
- frequency of intimacy-inducing-behaviour	IBCS-19

Sexual (dis)satisfaction; According to the sexual scripting theory and the social learning theory, sexuality can only be evaluated in subjective terms because there is no such thing as "objective sexuality". Therefore evaluation of sexual functioning was operationalized in terms of personal subjective experiences. Only the individual subject is able to judge his or her sexual functioning as satisfying or dissatisfying.

An important problem in quality of life research is the amount of restriction in the domain people are asked to evaluate. In this case sexuality can be evaluated in a strict sense, e.g. "If you only have to look at yourself at the present time how

satisfied are you with your sexual life in a strict sense?". However, sexuality can also be evaluated in a more broad sense, e.g."Seen in the light of everything what has happened the last months, how satisfied are you with your sexual life in general?". For practical reasons and because we expected that in the strict context of sexuality changes would be most closely connected with sexual dissatisfaction, the term "sexual dissatisfaction" was chosen as the first measure of importance for sexual functioning in the study. Given the important component of relatedness in (female) sexuality a distinction is made between sexual dissatisfaction from the personal individual perspective, i.e. the "personal sexual dissatisfaction" and "sexual dissatisfaction within the context of partner relationship", i.e. the relational sexual dissatisfaction.

With regard to our question to evaluate sexual functioning in a more broad sense "general sexual satisfaction" was taken as a measure.

Operationalization:

- personal sexual dissatisfaction	IBCS-6
- relational sexual dissatisfaction	IBCS-5
- general sexual satisfaction	IBCS-GSS

The sexual response; The capacity to experience and induce feelings of sexual excitement and orgasm is defined by Masters and Johnson[7] as the sexual response. Initially in this study three distinct aspects of the sexual response cycle were investigated separately, i.e. genital feelings of sexual arousal, feelings of orgasm and the capacity to induce sexual arousal and orgasm. Later these three aspects were recombined to the Groningen Arousability Scale F-version (see chapter 6.3). In this study the initial version was used.

Operationalization:

- genital sensations during arousal	GSSUM *
- orgastic sensations	OSSUM *
- capacity to induce sexual arousal and orgasm	CAPSUM *
- negative genital sensations during sexual intercourse	NEGSUM *

5.3.3 Covariables

More peripheral parts of the model are the psychological, physical and social variables which are also dependent on cancer treatment and interrelated with sexual motivation, behaviour, satisfaction and response.

5.3.3.1 Psychosexual variables

Body-image; because gynaecological cancer treatment may have a mutilating effect on the female body, the actual appreciation in terms of attractiveness of parts of the body, including the genitals, was measured as well as the importance of their appearance.

* The scales marked with an asterisk were specially designed for this study. The abbreviations refer to the sumscore of the measured concept e.g. GSSUM is the sumscore of all items covering genital sensations during sexual arousal.

Operationalization:

- attractiveness of body parts	GBIS-A *
- importance of body parts	GBIS-B *

Self-esteem; closely related to the concept of body image is the concept of self-esteem. In this study self-esteem is investigated in terms of self-esteem in sexual situations.

Operationalization:

- self-esteem as a sexual partner	IBCS-16

Cognitive distractive mood disturbances; fear and depression as well as other less specific mood disturbances were measured.

Operationalization:

- frequency of mood disturbances	IBCS-13

Appreciation of the partner. Sexuality in general comprises a relational component. Here the appreciation of the partner in general, as well as the appreciation of the partner as a sexual partner were measured.

Operationalization:

- appreciation of the partner relationship in general	IBCS-AP
- appreciation of the partner as a sexual partner	IBCS-17

Sexe role rigidity; It was hypothesized that, given the physical changes induced by the treatment, the flexibility in sexe role behaviour could be an important factor for the sexual adaptation process afterwards. The concept of sexe role rigidity is according to Vennix[8] closely connected to the concept of self confidence and self assurance.

Operationalization:

- self-confidence in social situations	IBCS-P1
- self-assurance	IBCS-P2

5.3.3.2 Physical variables

As was discussed before a number of physical conditions have to be fulfilled to make the sexual response possible. In the first place bodily i.c. genital sensations have to be perceived. In the second place these perceived sensations have to be experienced as "sexual" i.e. have to be labeled as sexually exciting. The first issue is studied by measuring *genital sensitivity* , which will be discussed later (see chapter 6.2) and the latter by measuring the sexual response, which was discussed earlier (5.3.2). Additional physical variables measured in the study are:

- vaginal shortening
- vaginal stenosis
- medication.

Operationalization:
- Medical Checklist
- Medical Examination

5.3.3.3 Psychological variables

Initially it was the purpose to include in this study also some more general psychological or personality variables. The choice of these variables was rather arbitrary because no earlier research was available to guide it but based on general literature on health psychology of last decade the following "traits" were selected: coping, internal/external locus of control, state and trait anxiety and social support.

In practice, however, it appeared that in combination with the already included scales, the assessment of these personality factors would possibly overburden the patients. Moreover, these variables were not primarily included in our theoretical framework. Therefore it was decided to administer these personality scales only in a very limited number of cases, more or less as a pilot study for further future research. The results of this pilot data gathering during this study were too limited to include them here. They will be reported on as soon as a sufficient amount of data becomes available.

An exception however was made with regard to "past experiences" because data about this were already available from the pre-treatment assessment.

Past experiences; A special type of personality variable is one's personal sexual history. According to the Social Learning Theory one's present sexual behaviour is partly determined by earlier sexual experiences. Because no real prospective design could be used this variable could only be operationalized by using retrospective reports of the patients over a period of one months before the onset of their complaints or the coincidental discovery of their disease.

Operationalization:

- frequency of sexual arousal (retrospective)	IBCS-2
- frequency of intimacy (retrospective)	IBCS-1
- freqency of sexual arousal-inducing-behaviour (retrospective)	IBCS-20
- frequency of intimacy-inducing-behaviour (retrospective)	IBCS-19

5.3.4 Confounding variables

Confounding variables included demographic variables such as age, religion, marital status and years of marriage/steady relationship and level of education. A special variable which has to be emphasized here is the level of sexual education. In the literature it is hypothesized that the presence of myths and misinformation on sexual matters may play an interfering role with sexual rehabilitation. However, as it seemed unrealistic to measure "knowledge" of sexual functioning in general and after gynaecological cancer in particular, this variable was not measured. To rule out the influence of this factor as much as possible, it was decided to provide all participating women and their partners the same, detailed information. Therefore an information booklet about gynaecological cancer treatment was written that included information about the sexual consequences of the disease and its treatment. It was assumed that, by giving access to this information and by verbal information, all patients in the experimental population of the research project would receive the same amount of information.

When the research project started there was no information booklet on this issue nationwide. Later on the Dutch Cancer Society used the content of the booklet for their information service.

Operationalization:

- Demographic Checklist

5.3.5 Additional psychometric information on the questionnaires and checklists

5.3.5.1 Population norms

If norms were available of certain measures of sexual functioning, these norms were used. For those measures for which norms were not available, a sample of gynaecologically healthy women was included in the study.

5.3.5.2 Scoring of the questionnaires

All of the above mentioned scales of the IBCS (except the IBCS-GSS) are scored according to the same principle i.e. the scores reflect the expectation of the respondent (in percentages) of the measured variable to occur during sexual interaction. This does not mean that a respondent gives e.g. her estimation of certain feelings to occur in percentages. The respondent fills in a number of multiple choice items (with answer categories like always, often, seldom and never) and based on these items a percentage score is calculated, which is supposed to reflect the chance that this particular feeling will occur during sexual interaction. For example a score of 80 on the NEGSUM means that the respondent has a relatively high expectation i.e. 80% that negative sensations will occur during sexual interaction. By tranforming all scales into "expectation percentages" not only an operationalization is chosen which corresponds most to the theoretical starting points of Rotter's theory on social learning but also a uniformity in scoringsrange is established, which eases comparison of scores on different scales. To transform the original scores into expectation percentages the following formula was used:

endscore = (sum - Nfi) * [100/(C-1)]/ Nfi

sum: raw sumscore of all items
Nfi: number of items that were filled in
C : number of answer categories of the items of a scale

The IBS-GSS

The IBCS-GGS scores were not transformed into expectation perecentage scores because this scale does not measure an expectation but rather a global retrospection on sexual functioning in general.

Both the transformation of all other IBCS scales and the not-transformation of the IBCS-GSS are conform the original manual.[8]

5.3.5.3 The interviews

In addition to the questionnaires data on sexual functioning were gathered by means of individual structured interviews and psychophysiological measurements. The interviews served more then one function in this study:

- during the interviews the participants could express their feelings in a more personal and direct way to the investigators;
- the data of the interviews formed an extra source of information, especially of that type of information that could not be gathered by means of questionnaires, e.g. whether certain typically personal circumstances played a role in the process of sexual rehabilitation;
- the data from the interviews could be used as a cross-validation of the results of the questionnaires.

For practical reasons unfortunately only the group of gynaecological cancer patients and their partners could be interviewed, so no data on the control- or comparison groups on this matter are available. The procedure during and after the interviews was as follows:

Patients

Each patient was interviewed by a female psychologist 12 months post-treatment. The interviews took place in the hospital and lasted about three quarters of an hour to one and a half hours. All patients gave permission in advance for taperecording. The patients and the psychologist were unfamiliar with each other and the psychologist was ignorant about detailed aspects of the patient's disease and treatment. To score the interviews, content analysis was performed in which the patients responses were scored on a ordinal level by two female psychologists independently, using the original taperecordings of the interviews and fully written versions of the interviews.

In the interviews special attention was given to subjective changes in the following aspects of sexual functioning:

- sexual activity
- feelings of sexual arousal and orgasm
- sexual motivation
- sexual satisfaction.

Partners

All partners who consented to participate were males. They were all interviewed by a male psychologist. The mean age of this population was 51 years with a range of 33 to 70. All participants had long lasting relationships which means that they were married or were living together for at least five years. Data gathering and analysing procedures were identical to those of the patient population. The issues of discussion, however, were different and could be clustered around two central themes: "involvement and support"and "sexuality and relationship". Classified around these two themes the following eleven topics were discussed:

Involvement and support

- feelings about the treatment procedure, i.c. received information and support from the hospital staff
- ideas about the future (prognosis)
- experienced psychological stress during the past year
- (need for) contact with other partners or therapeutic aid
- changes in life-attitudes
- support given to the patient.

Sexuality and relationship

- quality of the relationship in general during the past year
- quality of the sexual relationship before the treatment and during the past year
- improvement of the relationship because of the experiences of the last year
- the presence of sexual problems due to illness or treatment
- the occurrence of sexual rehabilitation.

5.3.5.4 Psychophysiological assessment

This type of measurement was not available at the start of the project and therefore had to be developed during the study.

Details of this assessment are provided in chapter 6.2.

REFERENCES

1. YATES, J.W. (1984) Common errors in psycho-social research in cancer. In: J.C. Holland (Ed.) Current concepts in psycho-oncology. New York, Memorial Sloan-Kettering Cancer Center, pp. 85-87.
2. VINCENT, C.E, VINCENT, B., GREISS, F.C. & LINTON, E.G. (1975) Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
3. MAGUIRE, G.P., LEE, E.G., BEVINGTON, D.J., KUCHEMANN, C.S., CRABTREE, R.J. & CORNELL, C.E. (1978) Psychiatric problems in the first year after mastectomy. British Medical Journal, 1, pp. 963-965.
4. MORRIS, T., GREER, H.S. & WHITE, P. (1977) Psychological and social adjustment to mastectomy. Cancer, 40, pp. 2381-2387.
5. WIJMA, K. (1984) Psychological functioning after hysterectomy. Groningen, Dissertation.
6. ROTTER, J.B. (1954) Social learning and clinical psychology. Englewood Cliffs, N.J., Prentice-Hall.
7. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
8. VENNIX, P. (1983) De ILKS gedachte. Zeist, NISSO.
9. VENNIX, P. (1989) Seks en sekse. Delft, Eburon.

Chapter 6

The empirical studies

6.1 Sexual rehabilitation of radical vulvectomy patients. A pilot study*

Summary

Ten women, who had undergone radical vulvectomy for cancer of the vulva, and their partners were interviewed on average nearly 2 years after the operation. In spite of many problems 8 out of 10 couples accomplished complete or partial sexual rehabilitation. For two couples only there seemed to be no return to sexual activity. The authors conclude that sexual rehabilitation after radical vulvectomy may be expected. But, sufficient information, sufficient coping, and sufficient communication does not guarantee complete sexual rehabilitation. It is suggested that motivation for sexual expression and mutual affection might be more important for sexual rehabilitation than any physical restrictions imposed by the surgery.

6.1.1 Introduction

Cancer of the vulva is the fourth most common female genital malignancy accounting for approximately 5% of all gynaecological cancers. The average age of women confronted with this disease is 63 years.

Radical vulvectomy is the standard treatment. Radical vulvectomy includes removal of labia majora and minora, removal of the clitoris, mons veneris, surrounding tissue and frequently extensive lymph node dissection. This operations gives hope for survival but is severely disfiguring. In spite of this there has not been any large-scale prospective study of the psychosexual adjustment of women following radical vulvectomy.[1]

Compared to other fields of cancer research, psychosexual functioning after radical vulvectomy is extremely neglected. If there is any attention at all paid to sexuality after radical vulvectomy the information given is extremely limited.[2-4] Up till now only two articles in the literature give more extensive information about psychosexual functioning after radical vulvectomy. In 1983 Andersen and Hacker[5] presented a comprehensive post-treatment assessment of current psychosocial/sexual adjustment of 15 patients. At the time of the interview the mean age of the sample was 55 years (range 30-85 years), with an average interval since vulvar surgery being 5 years (range 1-18 years). Using self-report measures which had previously demonstrated reasonable reliability and validity they found 'reasonable social adjustment, notable psychological distress and a significant disruption in sexual functioning and body image'. Most women felt that information regarding sexuality

* W.C.M. Weijmar Schultz, K. Wijma, H.B.M. van de Wiel, J. Bouma & J. Janssens (1986) Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 119-126.

was either absent or falsely reasurring. The authors note that the importance of their effort is limited by the absence of pre-treatment observations, repeated assessment, and comparison groups.

In 1983 Moth et al.[6] published a preliminary report on sexual functioning and somatopsychic reactions after vulvectomy. They questioned 14 women and their partners 1-8 years after radical vulvectomy. In this study patients with pre-cancerous lesions were included. The average age of the patients was 49 years (range 32-60 years). Questionnaires were specially formulated for this study. They found 1-8 years after the operation that about half of the patient had given up coitus. More than 2/3 of the women experienced pain during coitus and almost all experienced clear changes in their sexuality. Before the operation 13 of 15 women functioned well; after the operation 7 had stopped sexual activity (due to dyspareunia), 5 had decreased libido as well as orgasmic dysfunction, and 1 reported insufficient vaginal lubrication. Furthermore, they found changes in the women's mood, feminine self-concept, body acceptance, and self-confidence. Less than half of the women mentioned the information provided as 'good' or 'excellent'. Only 1 among 9 partners mentioned that the information was 'only adequate'.

Study of the psychological adjustment of patients following treatment of cancer of the vulva needs prospective research. In our clinic prospective research on sexuality in cancer patients has been started. Patients with carcinoma of the vulva and their partners will be included. In preparation of this pre-post-treatment project, a pilot study was done. Although limited, the study contributes to further prospective research.

6.1.2 Methods

In the Department of Gynaecology of the Groningen University every year about 15 women are treated for carcinoma of the vulva. Twelve couples were invited to participate in a pilot study to evaluate post-treatment sexual rehabilitation according to the following inclusion criteria: (1) married, (2) age under 70, (3) absence of somatic and/or mental affections in one or both members of the couples that might influence the sexual relationship, and (4) the absence of recurrence of the disease or additional treatment. Ten couples were willing to participate, nearly 2 years after a radical vulvectomy including clitoridectomy and bilateral inguinal and femoral lymph node dissection (range 1-6 years). All patients had been informed of the diagnosis of cancer before or during their stay in the hospital, prior to surgery. The average age of the women at the time of the operation was 54 years (range 27-69 years). One couple did not have children. The remaining couples had an average of 2.7 children, the youngest child being one year old and postoperatively conceived and born per vagina.

A self-report questionnaire was completed in the hospital in the presence of the first author. A summary of the questionnaire is represented in Table 1.

Special attention was paid to (1) information, (2) coping, (3) communication, and (4) sexuality. Patient and spouse received both slightly different questionnaires. 'Sexuality' was defined to the couples as 'every form of intimate body contact' in order to have not only coital contacts reported. After completing the questionnaire

Table 1 Summary of the questionnaire (108 questions)

1.	Social situation	Age; civil status; religion, educational level; profession; number of children.
2.	Somatic history	Earlier severe somatic disease.
3.	Psychiatric history	
4.	Present life situation	Anxiety; depression; guilt; preoccupation; communication; self-acceptance; resumption of work; attitude towards work; appearance in public; feelings about coping with the disease.
5.	Information	Preoperative information; quality of information; information about sexuality; satisfaction with information.
6.	Communication	Communication in the hospital and at home; persons to communicate with; contact with other vulvectomy patients; participation in a discussion group.
7.	Sexuality	Pre- and postoperative sexual desires and/or feelings; intimate body contact; coital frequency; dyspareunia; satisfaction with sexual activity; orgasmic feelings; masturbation; communication about sexuality; expectations about sexual rehabilitation; intimate body contact in a non-coital way.

the opportunity was given for discussion. Finally the women were submitted to a gynaecological examination to verify whether the vaginal introitus was adequate for coitus.

Information, coping and communications were classified as sufficient according to specific criteria. The information was classified as sufficient if satisfactory information about the disease and its treatment and about the sexual consequences had been obtained. Coping was classified as sufficient if there were no symptoms of fear or depression, no problems with self-acceptance, appearance in public, female identity and self-esteem, talking about the disease, occupational and social recovery and if a positive feeling about coping with the disease existed. Communication was classified as sufficient if satisfactory contacts existed with the partner and other people in the hospital as well as at home.

Sexual rehabilitation was classified as complete, partial or none. Sexual rehabilitation was classified as complete if both partners mentioned no decrease in sexual desires and/or feelings postoperatively, if no change in intimate body contact, including coitus, had been experienced and if orgasmic feelings, if originally present, had returned. Sexual rehabilitation was classified as partial if resumption of sexual activity had occured but not fulfilling criteria for complete sexual rehabilitation. Sexual rehabilitation was classified as none if hardly any intimate body contact was present postoperatively.

The classification offered the opportunity to compare the quality of the information, coping and communication with the quality of the sexual rehabilitation.

6.1.3 Results

Findings related to the information

The information from professional helpers (gynaecologist, nurse, family doctor) about the disease and its treatment and about the sexual consequences was estimated as sufficient by half of the female participants (Table II). Preoperatively 8 women wondered how they could continue their sexual relationship after the operation. Six of them discussed sexuality before the operation with the gynaecologist, family doctor or husband. Only 3 men mentioned that they had asked themselves preoperatively how the sexual relationship would be after the operation, but no one had discussed it with anybody else, reasons being: 'my wife was sorrowful enough', and 'let's first see what happens after the operation'. Retrospectively 8 women and 9 men considered it useful that the sexual aspect of radical vulvectomy be raised by the gynaecologist before the surgery.

Findings related to the coping with the disease

Coping with the disease was classified as sufficient for 4 women and insufficient for 6 women (Table II). Among the last were the two youngest patients, 27 and 32 years old at the time of the operation. Both had to deal with severe problems within their relationship. For one of them these problems existed already before she suffered from carcinoma of the vulva. Because of these problems psychological help was needed for both. Another patient, whose coping was classified as insufficient, had been treated in the past by a psychiatrist for marital problems. She had remarried 4 years before the operation and mentioned that she had had to cope with her husband's poor coping with the illness.

Table II Incidence of sufficient information, coping and communication of the female partner and the degree of sexual rehabilitation in 10 couples, on average nearly 2 years after radical vulvectomy

Age		Sufficient			Sexual rehabilitation		
Male	Female	Information	Coping	Communication	Complete	Partial	None
34	32					+	
28	27			+	+		
41	41		+	+	+		
45	43	+	+	+	+		
50	50	+			+		
53	58	+		+		+	
68	67					+	
67	67	+	+	+			+
69	68	+					+
68	63		+			+	

Findings related to the communication about the disease

Communications with others about the disease were classified as sufficient for 5 patients (Table II). Nine women were content with the degree of understanding on the part of their husband and their families and close friends. Nine women also had satisfactory contacts during their stay in the hospital with the medical and the nursing staff. Once the patient was home again the most important source of support was the husband, the family doctor, the children and the doctor at the out-patient department. Seven out of 10 women and all 10 men did not appreciate when, after discharge from the hospital, someone took the initiative to talk with them about the disease. Seven women thought it would be beneficial to get in touch with another vulvectomy patient. Five women but only one man thought it a good idea to participate in a discussion group. Five of the 10 women felt that the hospital made allowances for them as persons, but only 3 of the 10 spouses thought the hospital had consideration for them too. The husbands talked less about the disease with other people than their wives did. Husbands talked mostly with their wives, their family doctor, their children or their relatives.

Findings related to the sexuality

Compared with the sexual relationship before the operation retrospectively 4 out of the 10 couples had postoperatively a complete sexual rehabilitation. For 4 couples the sexual rehabilitation was partial, and for 2 couples there was no rehabilitation (Table II). Nine of the women and 8 men were satisfied with their sexual relationship postoperatively. Before the operation all couples had regularly intercourse. After the operation 7 couples resumed regular intercourse. None of the 4 couples above 60 years accomplished complete sexual rehabilitation. Preoperatively 9 women could experience orgasm; postoperatively 5 women could experience orgasm again. A patient, 52 years old, recounted that getting to experience an orgasm required more elaborate foreplay postoperatively. Literally she said: 'The orgasm has to be built up again'. Another patient, 51 years old, mentioned that other parts of the body compensated the absence of the clitoris. Two women mentioned returning sensitivity in the area of the clitoris.

6.1.4 Discussion

The number of patients interviewed is few and the information obtained is retrospective. However, the literature on sexual rehabilitation of radical vulvectomy patients is small and inclusion of the partner into the assessment process is frequently neglected. These results can provide preliminary information for future prospective research efforts.

Eight out of 10 couples accomplished complete or partial sexual rehabilitation after a radical vulvectomy. For 2 couples only there seemed to be no return to sexual activity. Both these couples were over 60 years old. Coital activity, before the operation present in all 10 couples, took place in 7 couples. Before surgery 9 out of 10 women could experience orgasm, after surgery 5 women could experience orgasms again. Prior to surgery all participants in the interview reported satisfaction with their sexual relationship. After surgery 9 women and 8 men reported satisfaction

with the sexual relationship in spite of the fact that 6 couples reported no or only partial sexual rehabilitation. Thus, significant sexual change is not always reported as negative.

It is still unknown which somatic and which psychological variables contribute to sexual problems after cancer treatment. Therefore, it is not clear whether one should search for other less disfiguring or disruptive kinds of treatment, which are less threatening to sexual body functions and appearance,[4] or whether one should focus on ways of teaching patients how to deal with their changed bodily sensations and sexual capacities. Probably one should do both.

It is realized that the number of couples involved in this exploratory study is too small to measure the effect of any intervention on sexual rehabilitation. However, it appears from table II that, even if the quality of information, coping and communication are classified as sufficient, this does not automatically result in complete sexual rehabilitation nor do insufficient information, coping and communication exclude complete sexual rehabilitation. Apart from physical restrictions, lack of motivation might be the reason for the absence of complete sexual rehabilitation for the people over the age of 60. Sexuality may not appeal to them anymore, they may easily reconcile themselves to different circumstances, which might mean that they may not be so strongly motivated. Besides, while talking with the couples, irrespective of age, motivation for sexual activity appeared to be a returning topic closely related to the extent of mutual affection felt. This is in agreement with the statement of Andersen and Hacker[5] that 'the presence of a healthy and interested partner appears to be the variable of critical importance to the maintenance of female sexual activity rather that age'. For some of our couples sexual intercourse took place only for the sake of the male partner, while it did not appeal to the female partner at all: the patient apparently resumed sexual activity because of the affection for her partner. It is also possible that fear of losing the partner plays an important role. There is still very little known about the influence of the partner on sexual rehabilitation of the patient. In general, the partner has to be nice, understanding and supportive, but yet no recommendations were given to help him or his partner realize these tasks.

Little is known about an individual's sexual motivation when confronted with cancer. We do know that the desire for coitus decreases but this is only one aspect of what could be termed 'sexual motivation'. Drähne et al.,[7] for example, found that the need for touching and caressing increased, both for the patient and her partner. Thus, instead of a decrease in sexual motivation they found a shift in the types of sexual activity desired. When cancer leads to such a shift and, for instance, coitus is no longer desired by both partners, there may be no sexual problem at all.

If, in the literature, there is any attention at all paid to sexuality, you will often find the same general remark: "Libido and coitus frequency are reduced." Since such minimal information tells us very little about the reason for this reduction or about other aspects of sexual functioning such as sexual emotions or non-coital sexual behaviour, the information we can provide to our patients concerning sexual matters is limited. This might be one of the reasons that in our study, as well as in the studies performed by Andersen and Hacker[5] and Moth et al.,[6] the quality of information

appeared to be insufficient, especially information given to the partner. Patients want to know what the consequences of cancer and its treatment are for their sexual functioning. These days more and more patients ask questions about sexuality and more and more doctors are criticized for giving attention only to medical-technical parts of the treatment. Many women seek attention to 'quality of life' concerns, including sexuality. It is known from the literature that 70-80% of cancer patients would have liked to have had information about sexuality: this in contrast to the doctors, of whom more that 50% thought that they had given sufficient information about sexuality.[8] It is very surprising that, after discharge from the hospital, 7 out of 10 women and all of the 10 men did not appreciate it when someone took the initiative to talk with them about the disease.

Preliminary conclusions:

- sexual rehabilitation may be expected following radical vulvectomy for cancer of the vulva.
- motivation for sexual expression, closely related to the extent of mutual affection felt, might be more important for sexual rehabilitation than any physical restrictions imposed by the surgery.

To test the validity of this observation prospective research is needed on a greater number of patients and with application of appropriate standardized instruments to measure a complex of variables which might contribute to sexual difficulties.

Finally, it is remarkable that orgasm was reestablished in at least 5 women. This, together with the findings of other authors,[5,6,9-11] confirms that mutilating surgery of the female organ including clitoridectomy does not mean loss of the ability to achieve orgasm. The loss of such sexual responsive tissue may be compensated by sexual responsiveness in other parts of the body or feelings. It demonstrates the complex character of the feeling we call orgasm and the capacity of the body and, most important, of the mind to adjust to special circumstances.

REFERENCES

1. ANDERSEN, B.L. & HACKER, N.F. (1983) Psychosexual adjustment of gynecologic oncology patients: a proposed model for future investigation. Gynecologic Oncology, 15, pp. 214-223.
2. CHEEK, D.B., (1976) Hypnotherapy for secondary frigidity after radical surgery for gynecological cancer: two case reports. American Journal of Clinical Hypnosis, 18, pp. 13-19.
3. SPRINGER, M. (1982) Radical vulvectomy: physical, psychological, social, and sexual implications. Oncology Nursing Forum, 9, p. 19.
4. DISAIA, R.J., CREASMAN, W.T. & RICH, W.M. (1979) An alternate approach to early cancer of the vulva. American Journal of Obstetrics and Gynecology, 133, pp. 825-832.
5. ANDERSEN, B.L. & HACKER, N.F. (1983) Psychosexual adjustment following vulvar surgery. Obstetrics and Gynecology, 62, pp. 457-462.

6. MOTH, J., ANDREASSON, B., BUIS JENSEN, S. & BOCK, J.E. (1983) Sexual function and somatopsychic reactions after vulvectomy, a preliminary report. Danish Medical Bulletin, 30, pp. 27-30.
7. DRäHNE, A., KAUFMANN, J. & KUNZ, S. (1979) Dealing with patients suffering from cancer. In: L. Carenza & L. Zichella (Eds.) Emotion and Reproduction, Vol. A. London, Academic Press, pp. 1327-1330.
8. BULLARD, D.G., CAUSEY, G.G., NEWMAN, A.B., ORLOFF, R., SCHANCHE, K. & WALLACE, D.H. (1980) Sexual health care and cancer: a needs assessment. In: J.M. Vaeth (Ed.) Frontiers of radiation therapy and oncology, 14, Basel, Karger S, pp. 55-58.
9. BROWN, R.S., HADDOX, V., POSADA, A. & RUBIO, A. (1972) Social and psychological adjustment following pelvic exenteration. American Journal of Obstetrics and Gynecology, 114, pp. 162-171.
10. DEMPSEY, G.M., BUCHSBAUM, J.J. & MORRISON, J. (1975) Psychological adjustment to pelvic exenteration. Gynecologic Oncology, 3, pp. 325-334.
11. LAMONT, J.A., DE PETILLO, A.D. & SARGEANT, E.J. (1978) Psychological rehabilitation and exenterative surgery. Gynecologic Oncology, 6, pp. 236-242.

6.2 Vaginal sensitivity to electric stimuli, theoretical and practical implications*

Summary

Vaginal sensitivity was investigated in a group of 60 volunteers by means of an electric stimulus and under nonerotic conditions. In comparison to the dorsum of the hand, the genital area has a low sensitivity for electric stimuli ($p < .001$). Of the genital area, the vaginal wall measured 2 to 4 cm from the vaginal introitus was found to be very insensitive ($p < .05$). Within the vaginal wall a relatively sensitive position to electric stimuli could be detected at the "12 hr position" (the anterior vaginal wall) ($p < .001$). The study provides data underscoring previous anatomical and clinical research findings regarding the sensitivity of the anterior vaginal wall. The inefficiency of coitus for inducing female orgasm is discussed.

6.2.1 Introduction

"Vaginal insertion" forms a substantial part of sexual behaviour, but the sensitivity of the vaginal wall is still a debated subject. Under nonerotic conditions, 14% of women report perceiving instrumental tactile stimulation of the vaginal wall and 90% of women report perceiving instrumental pressure on the vaginal wall.[1] Under more erotic conditions vaginal sensitivity to digital pressure has been reported by many authors, most convincingly on the anterior vaginal wall.[2-8] However, data produced on this issue have not been consistent.

Replication studies are needed with special attention to the location, structure and incidence of sensitive zones on the vaginal wall and in less selected populations. Also neurophysiological research is necessary in order to clarify the neuroanatomical basis for the clinical research findings. Histological studies have revealed free

* W.C.M. Weijmar Schultz, H.B.M. van de Wiel, J.A. Klatter, B.E. Sturm & J. Nauta (1989). Archives of Sexual Behavior, 18, pp. 87-95.

nerve endings in and near the vaginal epithelium or forming plexuses around the blood vessels[9-12] and a more intense nerve supply between the bladder and the vaginal wall.[9,12] Proper stimulation of these nerve endings should make quantitative measurements of vaginal wall sensitivity possible. In this study an effort was made to test this assumption. The study forms part of a more extensive research project concerning the effect of cancer treatment on female sexual behaviour, one of the psychosexual variables measured being genital sensitivity.

6.2.2 Method

A method to measure sensitivity should meet four fundamental requirements: 1. The stimulus has to be measured in physical units, 2. the stimulus must induce a clearly detectable sensation but not hurt, 3. the stimulus must not induce tissue damage, and 4. the stimulus should be suitable for measurements at all desired locations. An electric stimulus was thought to be suitable for our purpose. A constant current electric stimulus was chosen because it is not affected by topological differences in the impedance of the skin which may otherwise bias the values when measuring sensitivity at various locations.[13]

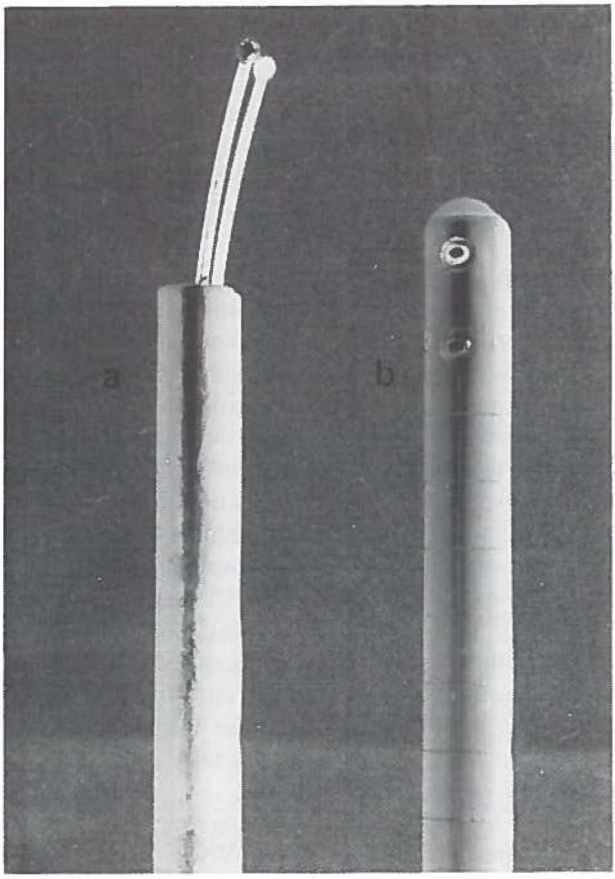


Figure 1 Stimulus electrode for the measurement of (a) external genital sensitivity and (b) internal genital sensitivity

For stimulation purposes a Neurolog pulse programmer (Digitimer Ltd, Serialno. NL 900-185), a square wave stimulator, a stimulus isolation unit and electrodes were used. The frequency of the stimulator was adjusted to 100 Hz and the impulse duration was 5 msec. Pulses were given in series of 20. The intensity of the stimulus current was adjustable, range 0-30 mA. The apparatus was accurately calibrated to within 0,05 mA.

The stimulus electrode had a conical stainless steel tip with a diameter of 4 mm, which was held against the site of stimulation. A low-resistance resilient construction provided standard pressure of the conical tip on the surface (Figure 1[a]). Electrode paste was used as the conducting medium. The indifferent electrode was a plate of stainless steel placed on the lower extremity. To measure the sensitivity of the vaginal wall a trofidur cylindrical tube was constructed (Figure 1[b]). Two conical stainless steel tips were positioned 1 cm from the top of the tube with a diameter of 4 mm as the stimulating electrode and the indifference electrode. The distance between the tips was 10 mm. This special construction was necessary because of the low sensitivity of the vaginal wall, which was found to be much lower than that of the skin of the lower extremity, the original site of the indifferent electrode in a pilot study. The Sensitivity Threshold (ST) is defined as the smallest intensity of an electric current, expressed in milliamperes, which, at a certain frequency and duration of the stimulus, evokes a slight prickly sensation.

Sixty healthy women, mean age 29 years (range 18 to 60, mode 24.0, median 27.1), visiting the hospital for contraception or contacted by advertisement, participated in the study. All woman, except two, 57 and 60 years old, had normal menstrual periods with or without oral contraceptives. The women were told that this study was part of a more extensive research project into the effects of cancer treatment on female sexual behaviour.

Measuring was performed by two female investigators (J.A.K. and B.E.S.) under nonerotic conditions. The method of instruction was standardized. No specific information about possible sensitive vaginal locations was given in order to prevent bias. The participating women were seated in a gynaecological chair in such a way that they could not see the testing apparatus. The women were instructed to report as soon as they perceived a prickly sensation. First the dorsum of the hand was stimulated to get used to the procedure and to learn to recognize the evoked sensation. The stimulus was increased slowly to the level at which the women could just perceive the prickly sensation. As soon as the women seemed familiar with the procedure the ST was estimated on the lower abdomen left and right, on the labia majora left and right, on the labia minora left and right and on the clitoris. The ST measurements at these locations were carried out three times, correlations assessed, and the average of each location calculated. The ST of the vaginal wall was measured in a random order at 12 different locations at a distance of 2 to 4 cm from the introitus of the vagina. All measured locations were at the same distance from the vaginal introitus. Measuring the ST at each location on the vaginal wall was done only once, in order to limit the duration of the procedure of vaginal measurement.

The results were analysed statistically by means of the following routines of SPSS-X: frequencies, *t*-test, reliability and repeated measures MANOVA.[14]

6.2.3 Results

The mean ST scores, measured at nongenital locations (dorsum of the hand, left and right lower abdomen), at external genital locations (left and right labium majora, left and right labium minora, clitoris), and at the internal genital locations (vaginal wall) are displayed in table I.

Table I Mean Sensitivity Threshold (ST), with Standard Error of the Mean (SEM), Standard Deviation (SD), Variability Coefficient (VAR), and Reliability Coefficient (α), as measured using electric stimuli on different locations

	MEAN ST	SEM	SD	VAR	α
Non genital locations					
dorsum of the hand	0.49	0.32	0.24	49.3	0.81
left lower abdomen	0.75	0.49	0.37	49.8	0.74
right lower abdomen	0.72	0.49	0.37	51.8	0.80
External genital locations[a]					
left labium majus	1.08	0.70	0.54	50.6	0.60
right labium majus	1.04	0.69	0.53	51.3	0.68
left labium minus	1.35	0.99	0.75	55.8	0.93
right labium minus	1.29	0.81	0.72	55.2	0.83
clitoris (n=60)	1.12	0.81	0.81	71.8	0.93
Internal genital locations[b]					
vaginal wall (n=58)	2.60	1.44	1.11	42.4	-

[a] Summary of univariate F tests comparing hand with abdomen (L1V2) and hand and abdomen with genitals (L12V3): for L1V2 $F(1,51) = 34.43$, $p < .000$, for L12V3 $F(1,51) = .44$, $p < .510$.

[b] Difference between vaginal wall and external genital locations: $t = 2.08$, $p < .05$.

No differences were detected between the ST scores at identical locations on the left and right side of the body. The ST scores obtained from the first, second en third measurements at each location correlated well (Mean= 0,79). At the clitoris a remarkable increased variability coefficient was calculated (VAR = 71,8). Repeated measure MANOVA on (A) location, (B) time, and (AB) interaction of location and time did reveal significant differences on location only (Table II).

Table II Summary of the Repeated Measures Analysis of Variance on the following effects: (A) Location, (B) Time, and (AB) Interaction of Location and Time

Effect	Wilks	Approx. F	Hypth. df	p
A	.49	26.05	2.00	$p < .000$
B	.99	.03	2.00	$p < .970$
AB	.97	.33	4.00	$p < .850$

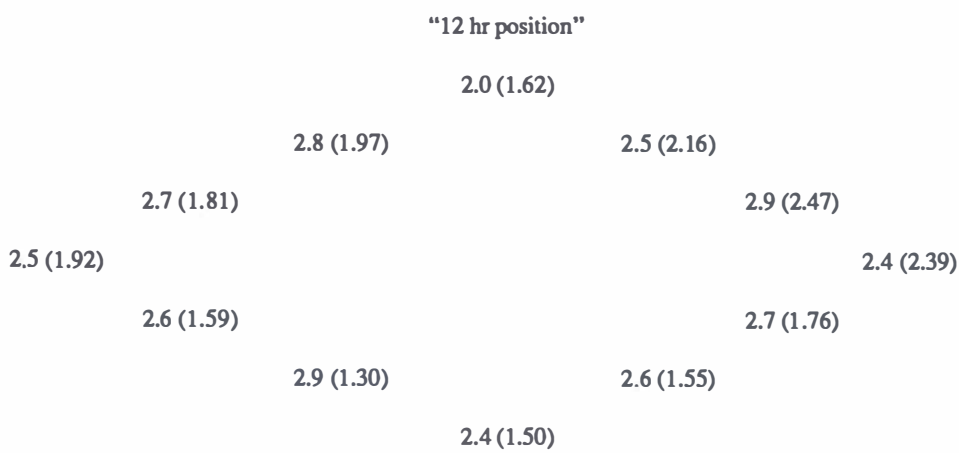
Higher ST scores were measured at the genital locations in comparison to the ST scores at the dorsum of the hand and the lower abdomen. Summary of univariate F-tests with df 1,51 on location, revealed that the difference in mean ST scores between the dorsum of hand and abdominal wall and the dorsum of hand and external genital locations was significant in contrast to the difference in mean ST score between abdominal wall and external genital locations (Table I, Footnote a). Within the genital area the mean ST score on the vaginal wall was very high. Student's *t* test showed a significant difference in mean ST scores between the vaginal wall and the external genital locations (Table I, Footnote b).

The mean ST scores at the various positions on the vaginal wall are depicted in fig. 2. Classification according to the level of ST measured, labelling the most sensitive position(s) as 1, the next most sensitive position(s) as 2, and so on, and statistical analyses of the difference in classification number of the "12 hr position" by chance and via the actual classification number

$$P(Xi=h)=\frac{1}{m} \quad h=1,\ldots,m; \qquad EXi=\frac{m+1}{2} \quad VARXi=\frac{m^2-1}{12}; \quad z=\sqrt{n}\,\frac{Xi-\frac{m+1}{2}}{\sqrt{\frac{m^2-1}{12}}}$$

revealed a highly significant increase in sensitivity on the vaginal wall at the 12 hr position, in comparison to the sensitivity at the other vaginal positions which were measured ($Z=4.81$, $p < .001$).

Fig. 2 The Mean Sensitivity Threshold, in milliamperes and standard deviation, measured in a random order at 12 different locations, 2 to 4 cm from the vagina introitus (n=58)



6.2.4 Discussion

To our knowledge, this is the first time that data on the sensitivity of the genital area to electric stimuli have been provided. It is obvious that in comparison to the dorsum of the hand, the genital area has a low sensitivity to electric stimuli, at least under nonerotic conditions. Of the genital area, the vaginal wall measured 2 to 4 cm from the vaginal introitus was found to be very insensitive. A relatively sensitive position to electric stimuli was detected on the vaginal wall at the 12 hr position (the anterior vaginal wall).

There are distinct differences in sensitivity between electric stimulation under nonerotic conditions and tactile stimulation under erotic conditions.[6,15,16] However, it can be assumed that at least some of the erotic stimuli reach perception via the nerve system measured in this study. In this respect, the conditions for the perception of erotic stimuli at these genital locations are inferior to those conditions elsewhere.

A low electric stimulus stimulates mostly nerve endings directly related to the vaginal wall. The discovery of a more intensive nerve supply between the bladder and the anterior vaginal wall on the one hand[9,12] and the increased anterior vaginal wall sensitivity found in this study on the other, support the contention that this specific nerve supply is the neuroanatomical origin of the electric sensitivity measured. From this contention, we do not expect the greater sensitivity of the anterior vaginal wall to be restricted to one specific spot. With the level of sexual arousal neurophysiological conditions may change but neuroanatomical conditions do not. Therefore, the nonerotic conditions under which this study was conducted do not explain the absence of more of these relatively sensitive positions, apart from the 12-hr position. This study provides data substructuring previous anatomical and clinical research findings regarding the sensitivity of the anterior vaginal wall.[2-8,17]

Other vaginal loci which are sensitive to rhythmic digital pressure, in particular the posterior-lateral vaginal wall[5,18-21] and the posterior vaginal wall,[8,17] might find their neuroanatomical origin within the tissues surrounding the vagina, not within the vaginal wall itself. These locations may not so much indicate vaginal sensitivity as pelvic sensitivity.

Stimulatory conditions were standardized as much as possible. The perceptual conditions between the participants are likely to be different, in particular when measuring "emotionally involved" organs. This was clearly reflected in an increased variability coefficient obtained at the clitoris. The increased variability in response might reflect the differences in emotional arousal caused by the procedure of applying the electric stimulus to the clitoris.

Many suggestions have been brought forward to help explain the relative inefficiency of coitus for inducing female orgasm, especially when it is compared with clitoral stimulation, for example, topographic and mechanical reasons,[8] a difference in the orgasmic latency between men and women,[1,7,22,23] the intensity of arousal,[15] the attitude and advice of experts -iatrogenic anorgasmy[4]- and the importance of emotional and relational factors.[24] These factors may be important, but we support the theory that the insensitivity of the vaginal wall, including the relatively sensitive anterior vaginal wall, is the main cause. It should be realized that, under the same low erotic conditions the sensitivity of the clitoris for electric stimuli is nearly twice

as high as the sensitivity of the anterior vaginal wall. This means that under identical stimulatory and perceptual conditions the sensitivity of the clitoris to stimuli surpasses the sensitivity of the vaginal wall. In other words, under identical stimulatory and perceptual conditions the contribution of the vaginal wall and even the contribution of the anterior vaginal wall to the sensory arm of the female orgasmic reflex[4,25] will be inferior to the contribution of the clitoris and may even be inferior to the contribution of more sensitive nongenital parts of the body. It is known that in the case of radical vulvectomy patients, without their clitoris, more elaborate foreplay is required to experience an orgasm. Also, sensitivity in the area of the clitoris can return or other nongenital parts of the body can compensate for the absence of the clitoris.[26] Compensation via the vaginal wall, or in particular the anterior vaginal wall, has not yet been reported by these women.

Alzate[17] and Hoch[4] have reported orgasmic responses by means of digital rhythmic pressure on the vaginal wall, in particular on the anterior vaginal wall. Whipple and Komisaruk[27] found that the anterior vaginal wall stimulation produced a significant increase in pain detection thresholds, whereas posterior vaginal wall stimulation did not. Hoch's proposed concept of a clitoral/vaginal sensory arm of the orgasmic reflex referes specifically to the anterior vaginal wall and the deeper situated tissues (urinary bladder, periurethral tissues, urethra and Halban's fascia) probably not reached by the low electric stimuli used in this study. Our findings support this concept with regard to the contribution of the anterior vaginal wall in particular being part and parcel of the female's clitoral/vaginal sensory arm of the orgasmic reflex with orgasmic potential when properly stimulated.

REFERENCES

1. KINSEY, A.C. POMEROY, W.B., MARTIN, C.E. & GEBHARD, P.H. (1953) Sexual Behaviour in the Human Female. Philadelphia, Saunders.
2. GRAFENBERG, E. (1950) The role of the urethra in female orgasm. International Journal of Sexuology, 3, pp. 145-148.
3. HOCH, Z. (1980) The female orgasmic reflex-its sensory arm. In: S. Sakamoto, S. Tojo & T. Nakayama (Eds.) Proceedings of the Ninth World Congress of Gynecology and Obstetrics. Amsterdam, Excerpta Medica, pp. 1268-1272.
4. HOCH, Z. (1986) Vaginal erotic sensitivity by sexual examination. Acta Obstetricia et Gynecologica Scandinavica, 65, pp. 767-773.
5. PERRY, J.D. & WHIPPLE, B. (1981) Pelvic muscle strength of female ejaculators; Evidence in support of a new theory of orgasm. Journal of Sexual Research, 17, pp. 22-39.
6. LADAS, A.K., WHIPPLE, B. & PERRY, J.D. (1982) The G Spot. New York, Holt, Rinehart and Winston.
7. GOLDBERG, D.C., WHIPPLE, B., FISHKIN, R.E., WAXMAN, H., FINK, P.J. & WEISBERG, M. (1983) The Grafenberg Spot and female ejaculation: A review of initial hypothesis. Journal of Sex and Marital Therapy, 9, pp. 27-37.
8. ALZATE, H. (1985) Vaginal Eroticism: A replication study. Archives of Sexual behavior 14, pp. 529-537.
9. KRANTZ, K.E. (1985) Innervation of the human vulva and vagina. Obstetrics and Gynecology, 12, pp. 382-396.

10. OWMAN, C., ROSENGREN, E. & SJöBERG, N.O. (1967) Adrenergic innervation of the human female reproductive organs: a histochemical and chemical investigation. Obstetrics and Gynecology, 30, p. 763.
11. BURGOS, M.H. & DE VARGAS-LINARES, R.C.E. (1978) In the Human Vagina. In: E.S.E. Hafez & F.N. Evans (Eds.) Amsterdam, North Holland Publishing Co., p. 63.
12. MINH, M.H., SMADJA, A., DE SIGALONY, J.P.H., Y. & AETHERR, J.F. (1981) Role du Fascia de Halban dans la physiologie orgasmique feminine. Cahiers de Sexuologie Clinique, 7, p. 169.
13. PROCACCI, P., ZOPPI, M., MARESCA, M. & ROMANO, S. (1974) Studies on the pain Treshold in Man. In: Advances in Neurology 4, New York, Raven Press, pp. 107-113.
14. SPSS-X User's guide (1983) New York, McGraw Hill.
15. ELLISON, C.R. (1984) Harmful Beliefs Affecting the Practice of Sex Therapy with Women. Psychotherapie, 21, pp. 327-333.
16. JAYNE, C. (1984) Freud, Grafenberg and the neglected vagina: thought concerning a historical omission in sexuology. Journal of Sexual Research, 20, pp. 212-215.
17. ALZATE, H. & LONDONO, M.L. (1984) Vaginal erotic sensitivity. Journal of Sex and Marital Therapy, 10, pp. 49-56.
18. KEGEL, A. (1952) Sexual functions of the pubococcygeal muscle. Western Journal of Surgery, 60, p. 521.
19. HARTMAN, W.E. & FITHIAN, M.A. (1982) In treatment of Sexual Dysfunction: a bio-social approach. Long Beach, California, Center for Marital and Sexual Studies, p. 77.
20. SEMMENS, J.P. & SEMMENS, F.J. (1978) Role of the vagina in female sexuality. In: E.S.E. Hafez & F.N. Evans (Eds.) In the human vagina. Amsterdam, North-Holland Publishing Co., p. 213.
21. GRABER, B. & KLINE-GRABER, G. (1979) Female orgasm: role of the pubo coccygeus. Journal of Clinical Psychology, 40, p. 34.
22. KINSEY, A.C., POMEROY, W.B. & MARTIN, C.E. (1948) Sexual behavior in the human male. Philadelphia, W.B. Saunders.
23. LEVITT, E. (1983) Estimating the Duration of Sexual Behaviour: A laboratory study. Archives of Sexual Behavior, 12, pp. 328-335.
24. BRUIJN, G.M. DE (1982) From masturbation to orgasm with a partner: how some women bridge the gap - and why others don't. Journal of Sex and Marital Therapy, 8, pp. 151-167.
25. KAPLAN, H.S. (1974) The New York Sex Therapy. New York, Brunner/Mazel.
26. WEIJMAR SCHULTZ, W.C.M., WIJMA, K., WIEL, H.B.M. VAN DE, BOUMA, J., & JANSSENS, J. (1986) Sexual rehabilitation of radical vulvectomy patients. A pilot study. Journal of Psychosomatic Obstetrics and Gynecology, 5, pp. 119-127.
27. WHIPPLE, B. & KOMISARUK, B.R. (1985) Elevation of pain threshold by vaginal stimulation in women. Pain, 21, pp. 357-367.

6.3 Self-assessment of sexual arousability and body-image in women; the construction of two questionnaires*

Summary

As part of a research project on sexual functioning after gynaecological cancer treatment, the aim of this study was to achieve a reliable means of assessment for the concepts "sexual arousability" and "body-image".

Sexual arousability was operationalized using four subscales: genital sensations during sexual arousal, genital sensations during orgasm, the capacity to (self-) induce sexual arousal and orgasm, and negative sensations during coitus.

Body-image was operationalized using two subscales: one assessing the importance which women attribute to certain parts of their body and one assessing the subjective degree of attractiveness of various parts of their body.

The data from nearly 200 assessments of 59 gynaecological patients and 60 healthy women were analyzed using the following three psychometric methods: item analysis per subscale via the classical test theory; item response theory per subscale and per total scale via the Mokken model for ordered answer categories; and item response theory per subscale and per total scale via the Rasch model for two answer categories.

The results confirmed that the scales were sufficiently reliable (in some cases after the omission of one or two items), with the exception of the subscale for negative sensations during coitus, which had insufficient structure to serve as an instrument to measure one underlying latent concept.

Based on the total item-pool, a new, highly reliable (α= .90) additional scale, measuring sexual arousability, could be distilled, the GAS-F. This 14-item scale also reflects the unidimensional and cumulative character of the sexual response.

6.3.1 Introduction

Treatment for gynaecological cancer often leads to substantial disruption of sexual functioning. Changes in body sensations during sexual arousal and pain during coitus are complaints which often occur. Diminished sexual motivation, arousability and capacity for orgasm are also reported frequently.[1,2] Apart from their direct impact on sexual functioning, certain treatment modalities, e.g. radical vulvectomy, may lead to such mutilation that sexual functioning is impaired by disruption of the body-image. Therefore, as part of a study on sexual functioning after gynaecological cancer treatment, an effort was made to operationalize sexual arousability, especially in relation to the perception of genital sensations during sexual arousal (the so-called "genital response"), and body-image.

In this article, an overview is given of the development and psychometric qualities of these operationalizations. First, however, a short description is provided of the theoretical concepts: sexual arousability and body-image.

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6.3.1.1 Genital response

According to Bancroft[3] sexual functioning can be regarded as a fine example of a "psychosomatic" process. In summary, Bancroft assumes in his theory that psychological processes, i.e. cognitions and perceptions, together with tactile stimuli, which do not necessesarily have to be perceived, cause changes in the limbic system and the spine. These centres in turn, activate the body to central and peripheral reactions, which include genital reactions.

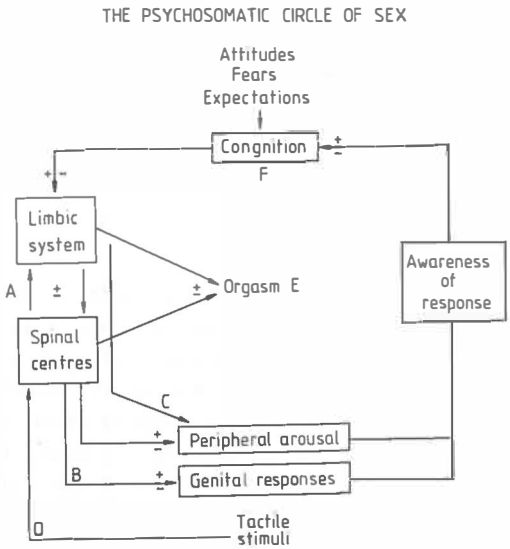

Figure 1 The psychosomatic circle of gen (after Bancroft [3]).

Awareness of these body changes may accelerate or slow down this circular process. If sexual arousal is positively rewarded and further stimulation is continued, the process reaches its peak, as well as its discharge, in orgasm. However, if sexual arousal is an undesirable or threatening phenomenon e.g. because it is accompanied by severe feelings of fear, the circular process will rapidly slow down and the experience of sexual arousal will stop. According to Bancroft, the cause of sexual dysfunctions can be reduced to plusses and minusses in the model. Although according to Bancroft, the cause of sexual dysfunction can primarily be found on a cognitive level, the study of genital responses and the perception of these responses can be highly relevant, especially if it is possible that the dysfunctions are related to physical changes, as is often the case after illness, handicap and/or medical treatment.

6.3.1.2 Body-image

In accordance with Groenman[4] we assume that the awareness of one's own body aspects and the subjective experience of these aspects, influence the self-concept and behaviour. In women especially the appearance of the breasts and genital area contribute substantially to the female identity.[5] Therefore, mutilation of these areas may lead to dramatic negative changes in sexual functioning.

Although the subjective experience of the genitals is widely accepted as being an important topic, hardly any studies have been carried out on women or men, dealing with the perception of one's own genitals and the attribution of certain meanings to them.[6]

6.3.2 Methods

Inventarisation of existing questionnaires revealed that no national operationalizations of sexual arousability and body image were available. International questionnaires on this topic were also very scarce and those available could not be aimed specifically at the Dutch situation without being adapted. Therefore it was decided to construct two new questionnaires: one for sexual arousability, the Groningen Arousability Scale (GAS) and one for body-image, the Groningen Body-Image Scale (GBIS).

6.3.2.1 The GAS

As a first step, a concept version of the GAS (Appendix 1) was made, based on the work of Masters and Johnson[7], Kaplan[8], Newcomb and Bentler[9] and of Hoon, Hoon and Wincze.[10] A number of items were selected from the American scales which measure genital sensations during sexual arousal (GSSUM). In view of the limited results of this selection referring to the entire sexual response as defined by Masters and Johnson[7] these items were combined with the following categories: sensations during orgasm (OSSUM), negative genital sensations during coitus (NEGSENS) and the capacity to self-induce sexual arousal and orgasm (CAPSUM). A total of 23 items were selected, divided into four subscales.

6.3.2.2 The GBIS

The GBIS (Appendix 2) was developed on the basis of a study on body awareness in women,[11] in which a self-assessment questionnaire was used to measure the importance women attribute to several parts of their body (including e.g. the genitals) and the subjective attractiveness of these parts. The GBIS has 27 items divided into two subscales, assessing the importance and attractiveness of various parts of the body, including the genital area, respectively.

6.3.2.3 Procedure

If items are chosen on the basis of previous research and substantive knowledge, it remains to be seen whether the items of a scale measure a common concept in a reliable way. In bygone days of "measurement by fiat", this point was largely neglected.

Nowadays, however, classical test theory, with key concepts such as true score,

item-rest correlation and test reliability, has meant a major step forward. During the past decade, there has been growing recognition that item response theory offers still better tools for assessing psychometric quality: if the data agree with the assumptions of such a measurement model, more insight is obtained into the structure of a scale and into the interpretation of a person's position on the scale. Therefore, to analyse the psychometric qualities of the first versions of our scales, and, if possible, to adapt them to produce the definitive scales, we used a combination of three psychometric methods:

- item analysis per subscale via classical test theory;
- item response theory per subscale and per total scale via the Mokken model for ordered answer categories;
- as above via the Rasch model for two answer categories.

6.3.2.3.1 Classical test theory For the items scored 1, 2, 3, 4 by the respondents, per subscale, the module RELIABILITY of SPSS-X[12] was used to obtain:

- the estimated total test reliability (Cronbach's alfa);
- alfa per item after its omission from the scale;
- the item-rest correlation per item.

6.3.2.3.2 Mokken model Mokken's non-parametric item response model[13] can be viewed as a probabilistic version of the Guttman scalogram. It not only orders the persons based on their total score, but also orders the items, i.e. the model predicts that respondents with the same total score, e.g. X=10, will have mostly given a positive answer to the ten most popular items and a negative answer to the remaining items. The model has been extended to handle more than two ordered answer categories[14] and is available in the form of a computer programme MSP.[15,16]

This programme not only tests whether a given (sub)test satisfies the model assumptions, but it also searches a given item bank for subtests which conform to the model. Both options were used per subtest as well as for the total GAS and GBIS. Guttman's reproducibility of the answer patterns is expressed by Loevinger's H–coefficient per item pair, per item and for the whole scale. Moreover, an estimate, rho, is obtained of test reliability.[17]

6.3.2.3.3 Rasch model For dichotomous items, the parametric item response model of Rasch[18] assumes that the probability of a positive answer is determined by the difference between a person parameter (position on the latent trait that the scale is intended to measure) and an item parameter (the trait value for which this probability equals 0.5). The computer programme PML[19] estimates these unknown parameters per person and per item and provides information on whether the data satisfy the measurement model. This procedure was applied both to the subscales and to the total GAS and GBIS (and if necessary repeated after badly fitting items had been deleted).

6.3.3 Results

Data description

In the period 1984-1988 the GAS, the GBIS and some biographical questions were administered to 60 women who participated in the research project "Sexual functioning after gynaecological cancer". A proportion of the respondents were treated for gynaecological cancer at the University Hospital Groningen, the others had to undergo hysterectomy for non-oncological reasons.
Data collection took place at three different times:

- a few days before surgery,
- at 6-months follow-up,
- at 12-months follow-up.

The same items were answered just once by a control group consisting of 59 healthy women (volunteers contacted by advertisement and women visiting the hospital for contraception).

The present paper reports on the psychometric aspects of the two scales only. For reports on the substantive research outcomes see Weijmar Schultz et al.[20]; Van de Wiel et al.[21,22] Owing to a number of drop-outs during the study period and incomplete answers to the questionnaires, this report is based on a varying number of respondents per (sub)scale for whom sufficient usable data were available. The total set of usable questionnaires was of sufficient size to allow us to draw reliable conclusions from the statistical analyses. Where necessary, reports were also made per subgroup; it is possible that the items in the healthy group produced different reactions than in the patient group and that the answers from the latter group changed over the course of time.

The age of our respondents varied from 18 to 69 years (mean 38 years). In the total group, 72% were married, 9% were living together with a partner and 19% were single. The relationships in the former two groups had a mean duration of 16 years (range between 1 year and 42 years). In the latter group, 23 women had a regular partner for a mean of 4 years, 3 had changing partners and 11 had no partner. In answer to a question on religion, 63% said that they belonged to a church; 13% mentioned that religion was very important to them, 24% fairly important, 30% said that it did not really play a role and 33% said that it did not play a role at all.

6.3.3.1 Classical item analysis

The subscale GSSUM of the GAS, genital sensations during excitement (items 1–9 in Appendix 1), had an estimated reliability (Cronbach's alpha) of 0.839. This rose slightly to 0.842 after omitting item 9 (numb feeling); this item had an item-rest correlation of 0.35 whereas this was at least 0.49 for the other eight items.

The subscale OSSUM of the GAS, feelings during orgasm, (items 10, 11, 13 and 14 in Appendix 1) had an alpha of 0.77 and a minimum item-rest correlation of 0.48 for item 14.

For the subscale CAPSUM of the GAS, capacity for self-induced arousal and orgasm (items 15-18, 22 and 23) the alpha was 0.79 with a minimum item-rest correlation of 0.42 for item 23.

The four items 12, 19, 20 and 21 (subscale NEGSENS intended to register negative sensations during arousal and orgasm) showed only a weak correlational structure (alpha = 0.60). After the omission of item 12 (a feeling of pain) with an item-rest correlation of 0.13, the alpha rose to 0.67. Therefore, it does not appear to be worthwile to view these items as meaningful indicators of a common concept "negative feelings". In a similar analysis of only the control group data, the alpha for OSSUM diminished from 0.77 to 0.58, whereas for the other subscales it was only slightly below the value for the total group. Within the patient group both at surgery and afterwards, the reliability per subscale was slightly higher than in the total group.

The first part of the GBIS (Appendix 2) comprises 13 questions about the importance of body aspects. This subscale had an alpha of 0.867, which rose slightly to 0.871 after the omission of item 7 (internal sexual organs). For the 12 ratings of attractiviness, in which the latter item was not included, the alpha was 0.83. Almost the same reliability values for the GBIS subscales were found in the various person subgroups.

6.3.3.2 Mokken analysis

The four subscales of the GAS turned out to satisfy the requirements of the cumulative Mokken scale, either fully or after the removal of one item, see lines a) to d) in the table below.

Table 1 Mokken scalability of the GAS and GBIS items

	# pers.	#items	H	reliab.	item numbers GAS
a)	173	8	.38	.86	1 2 3 4 5 6 7 8 (GSSUM, omit item 9)
b)	191	4	.45	.79	10 11 13 14 (OSSUM, complete)
c)	196	5	.44	.79	15 16 17 18 22 (CAPSUM, omit item 23)
d)	181	3	.39	.67	19 20 21 (NEGSENS, omit item 12)
e)	162	12	.40	.89	1 2 3 6 7 10 11 15 16 17 18 22
f)	162	12	.35	.87	1 2 3 4 5 6 7 8 9 10 11 15
g)	162	14	.36	.90	1 2 3 6 7 10 11 13 14 15 16 17 18 22
	# pers.	#items	H	reliab.	item numbers GBIS
h)	179	12	.47	.89	1 2 3 4 5 8 9 10 11 12 13 14
i)	179	10	.44	.85	15 16 17 18 19 21 22 23 24 25

Items 9, 23 and 12 were removed because their item scalability coefficients H(i) fell just below the recommended boundary of 0.30, an indication that the items showed too many violations of the cumulative Guttman structure. Inspection of the complete MSP output showed no signs of serious disturbance of the double monotony of the item trace lines assumed by the model. The four subscales had satisfactory values for both the total scale H and the reliability estimated using the Sijtsma and Molenaar[17] procedure. The number of respondents who completed all the items of the subscale varied between 173 and 196.

In the next step all 23 GAS items on 160 completed answer forms were analysed in order to check whether they measured the general concept "sexual feelings". This was not the case for the full scale. The four items with the lowest H(i) values were the four NEGSENS items 12, 19, 20 and 21, both in the original scoring order and after reversing their scoring direction. The 19 remaining items still did not form a good Mokken scale. The search algorithm produced the three partial scales listed as e) f) and g) in the table. Our conclusion is that the 14 items under g), with proportional numbers from the three subscales GSSUM, OSSUM and CAPSUM, form the best means of measuring such a general concept. The other two satisfied the cumulative Mokken model but posed some additional interpretation problems. The 14-item subscale in line g) will be therefore be regarded as a new scale, the Groningen Arousability Scale F(emale version) or GAS-F. The possibility of such a combined cumulative scale matches the sexual response model presented in section 1.

In the Mokken analysis of the GBIS, answer category 1 (very unimportant c.q. very unattractive) was combined with answer category 2, because it was chosen very infrequently and could have led to unreliable H-coefficient values.

Investigation per subscale revealed that neither the importance nor the attractiveness subscale fully satisfied the cumulative model, see lines h) and i) of the table, in which items 6, 7, 20, 26 and 27 had to be omitted. Further analysis per subgroup of respondents showed a moderate or poor fit for items 6, 7, 10, 12 and 14 of the importance scale and items 16, 20, 25, 26 and 27 of the attractiveness scale. This did not come as a surprise. A total score as a measure of general importance or attractiveness opposes the idea that specific aspects will be judged differently after surgery. The analysis per subgroup indeed showed some examples of this phenomenon.

Nevertheless, the high H values and reliability in lines h) and i) and the absence of serious violation of double monotony, indicate a cumulative structure. Thus, the frequency data in the Appendix imply e.g. that women who considered their face (item 1), style of behaviour (item 10) and general appearance (item 11) as unimportant, nearly always gave the answer "unimportant" for the other aspects; women who considered their buttocks (item 5) and thighs (item 8) as very important, generally also judged the other aspects as important. The cumulativity for women with the same low to high total scores, implies that it is often possible to predict which score categories per item have been chosen (this is what Guttman called the reproducibility of the answer pattern from the total score). The search algorithm applied to all 27 items neatly confirmed their division into an importance and an attractiveness subscale, although, here again, a few items were rejected because the H(i) values were too low or the H(i,j) values were negative.

6.3.3.3 Rasch analysis

For our situation with relatively few respondents and many items, it was considered desirable to avoid the use of the multicategory Rasch model and to dichotomize the scores (1 and 2 into a negative answer, 3 and 4 into a positive answer).

Starting from the a priori division of the GAS into subscales, acceptably fitting Rasch scales were attained for GSSUM and CAPSUM, with some doubt about items

9 and 23. The outcome was worse for the four OSSUM items. Here extreme popularity contributed to the conclusion of insufficient variability in the latent trait; (the estimated Index of Subject Separation, a Rasch counterpart of the classical reliability coefficient, even assumed a negative value!). For similar reasons, the four NEGSENS items failed to form a satisfactory Rasch scale.

The complete GAS scale of 23 items was not a good Rasch scale: the four NEGSENS items had insufficient discriminating power. This conclusion was based on their biserial correlations, on the U test for slope[19,23] and on the difference in item parameter estimates using the Andersen test for high versus low scoring persons. No improvement was observed after reversing the scoring direction.

The remaining 19 items formed a reasonable Rasch scale (KR20 = 0.86, ISS = 0.80, no U values >3, P=0.14 for the Andersen test high versus low).

Confirmation of the a priori division of the 19 items into three subscales was sought using splitter items.[23] The conclusion was that item 3 was somewhat problematic in the GSSUM scale, whereas items 10 and 11 could be added to this subscale, which agrees with line f) in the Mokken results table. The CAPSUM scale was nicely confirmed with the exception of item 23; item 1 could possibly be added. The OSSUM scale (only four items, of which 10 and 11 were extremely popular) was not well reproduced in the splitter analyses.

The 14-item importance subscale of the GBIS was not a good Rasch scale: KR-20 = 0.77, ISS = 0.36. There was a clustering of the high scores, items 6 and 7 were weak, 5 and 8 were doubtful. In the 13-item attractiveness subscale of the GBIS (KR20=0.77, ISS=0.59), items 16 and 26 fitted badly and item 20 moderately. Thus, the assessments of the sexual organs, items 6, 7 and 20, did not fit with the other replies. The attractiveness judgements of breasts (item 16) and hair (item 26) were also only weakly connected with the others. All 27 items of the GBIS formed a tolerable Rasch scale (KR-20 = 0.81, ISS = 0.69) with the worst fit for items 16 and 26.

Further analyses were performed to examine subgroups, such as control group, initial response versus responses after surgery, old versus young respondents, church members versus agnostics. In some cases, small sample sizes and skewed score distributions stood in the way of a completely satisfactory result, but at any rate, there was no clear violation of the Rasch requirement that item parameters should be the same in such subgroups.

6.3.4 Discussion

The valid and reliable measurement of attitudes by means of standardized questionnaire items is notoriously difficult. This is even more true for the emotional experiences in the forbidding domain of female sexuality. A numerical score calculated from the choices given in an answer category for a few written questions, must imply a dramatic reduction in the richness and variability of such emotions. On the other hand, our results showed that there was a substantial amount of structure in the answers, which opens the way to some meaningful substantive interpretation. For the unbiased comparison between groups or between measurement times, the availability of such a standardized instrument, with known psychometric quality, can be

useful. Particularly for individual diagnosis or counseling, the score on such a scale can be a good first step.

In rather complex problem areas, such as sexuality, involving e.g. the interplay of both physiological and psychological processes, heuristic ordering via a model like the psychosomatic circle of sexuality can be a tool for gaining an insight into changes in sexual functioning, which can occur e.g. after illness, handicap or medical intervention. As is also the case with other measurements in the behavioural and social sciences, a necessary condition is that the operationalizations used have sufficient quality to allow generalization to the world outside the research situation of filling in the questionnaire.

Although our results are based on a relatively small group of respondents, they provide confirmation that the scales were sufficiently reliable (in some cases after the omission of one or two items). An exception was the subscale for negative sensations during coitus, which had insufficient structure to serve as an instrument to measure one underlying latent concept.

The GAS-F scale, combining 14 items from the three other subscales, represents a general measure of sexual arousability that satisfies the cumulative Mokken model and thereby also reflects the unidimensional cumulative structure of the sexual response as described by Masters and Johnson.[7]

The use of scores at item level for the GBIS (self-judgements on the importance and attractiveness of various body aspects) will often be preferable to the use of scale scores, particularly if it can be expected that the evaluation of specific body parts changes after a medical intervention. However, when the main goal is to distinguish between women with a high opinion regarding the importance or attractiveness of their appearance and women with a low opinion, the positive results on the scalability of the two GBIS subscales are of great potential value.

REFERENCES

1. ANDERSEN, B.L. & HACKER N.F. (1983) Psychosexual adjustment of Gynecologic oncology patients: a proposed model for future investigation. Gynecologic Oncology, 15, pp. 214-223.
2. MANTELL, J.E. (1983) The psychosocial and physiological effects of invasive gynecologic cancers on female sexuality. In: L. Dennerstein & M. De Senarclens (Eds.) The young woman: psychosomatic aspects of Obstetrics and Gynecology. Amsterdam: Exerpta Medica, pp. 398-408.
3. BANCROFT, J. (1983) Human sexuality and its problems. Edinburgh/London: Churchill Livingstone.
4. GROENMAN, N.H. (1978) Zelfbeeld en borstbeeld. Leiden, Stafleu.
5. KERN, S. (1977) Anatomie en noodlot; een cultuurgeschiedenis van het menselijk lichaam. Baarn, Bosch en Keuning.
6. WIJMA, K. & ARESKOG-WIJMA, B. (1984) Cultural influences on personal experiences of genitals in women from western countries, as focused in gynaecological practice. In: K. Wijma: Psychological functioning after hysterectomy. Groningen, Dissertation.
7. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
8. KAPLAN, H.S. (1979) Disorders of sexual desire. New York, Brunner/Mazel.

9 NEWCOMB, M. & BENTLER, P. (1983) Dimensions of subjective female orgasmic responsiveness. Journal of Consulting and Clinical Psychology, 44, pp. 862-877.
10. HOON, E.F., P.W. HOON & J.P. WINCZE (1976) An inventory for the measurement of female sexual arousability: The SAI. Archives of Sexual Behavior, 5, pp. 291-300.
11. THURKOW, F.G. (1985) Hoe denken vrouwen er zelf eigenlijk over? Internal publication University Hospital Groningen.
12. SPSS-X User's Guide edition 2 (1986) Chicago, SPSS Inc.
13. MOKKEN, R.J. & LEWIS, C. (1982) A nonparametric approach to the analysis of dichotomous item responses. Applied Psychological Measurement, 6, pp. 417-430.
14. MOLENAAR, I.W. (1982) Mokken scaling revisited. Kwantitatieve Methoden, 3, pp. 145-164.
15. DEBETS, P. & BROUWER, E. (1989) MSP User's Manual. Groningen, iec ProGAMMA.
16. DEBETS, P, E. BROUWER, SIJTSMA, K. & MOLENAAR, I.W. (1989) MSP. A computer program for item analysis according to a nonparametric IRT approach. Psychometrika, 54, pp. 534-536.
17. SIJTSMA, K. & MOLENAAR, I.W. (1987) Reliability of test scores in nonparametric item response theory. Psychometrika 52, pp. 79-97.
18. ANDRICH, D. (1988). Rasch models for measurement. Sage University Paper Series on Quantitative Applications in the Social Sciences. Beverly Hills, Sage Pubs, pp. 007-068.
19. MOLENAAR, I.W. (1990) PML-PC User's Manual. Groningen, iec ProGAMMA.
20. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, BOUMA, J. & JANSSENS, J. (1990) Evolvement of psychosexual functioning after treatment for cancer of the vulva, a prospective study. Cancer, 66, pp. 402-407.
21. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLLENSLEBEN, A., THURKOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecologic Oncology, IX, pp. 275-281.
22. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G., BOUMA, J. & VERHOEVEN, A.C. (1990) Sexual functioning of vulva carcinoma patients. Journal of Sexual and Marital Therapy, 5, pp. 73-82.
23. MOLENAAR, I.W. (1983) Some improved diagnostics for failure of the Rasch model. Psychometrika, 48, pp. 49-72.

6.4 Psychosexual functioning after the treatment of cancer of the vulva; A longitudinal study*

Summary

Ten couples, the women beginning treatment for carcinoma of the vulva, participated in a 2-year longitudinal study on sexual functioning before and after treatment. Sexual functioning was measured on admission and at 6, 12 and 24 months post-treatment. Sexual functioning was made operational in terms of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, and the perception of genital sensations of sexual arousal. An age-matched nonpatient control group was added to the study and the impact of physical variables was also evaluated. Within 1 year, all women who were sexually active before the treatment

* W.C.M. Weijmar Schultz, H.B.M. van de Wiel, J. Bouma, J. Janssens & J. Littlewood (1990) Cancer, 66, pp. 402-407.

had resumed their sexual activities. At the 6-month assessment an increase in relational sexual dissatisfaction could be detected. Over the remaining observation period the women's satisfaction with sexual interaction with the partner was not found to be different from their pre-treatment satisfaction and not different from the satisfaction in the control group, in spite of the physical damage and persisting poor perception of genital symptoms of sexual arousal during lovemaking. Satisfaction with sexual interaction with the partner under these circumstances appears to be more an expression of satisfaction with the intimate aspects of the sexual relationship than of satisfaction with the physiological arousal aspects of the sexual relationship. It is argued that psychological and social variables are more crucial for sexual rehabilitation than physical variables. Therefore, psychosocial issues constitute the most promising focus for intervention.

6.4.1 Introduction

Cancer is often looked on as a breaking point in life because it leads to considerable changes in how people regard themselves and their future. Moreover, treatment frequently results in irreversible physical damage which, in turn, brings about changes in patterns of behaviour.[1] One of these patterns of behaviour involves sexual functioning. It is very likely that sexual function will be affected as a result of gynaecological cancer and its treatment. Invasive cancer of the vulva, currently accounting for approximately 5% percent of all gynaecological cancers, means confrontation with severely disfiguring surgery. This surgery may include the loss of labia majora and minora, removal of the clitoris, mons veneris, surrounding tissues, and frequently extensive lymph node dissection. In the advanced stage of the disease additional radiation therapy is given.

Currently only brief, retrospective descriptions of the psychosexual outcome of patients after radical vulvectomy, are available. Generally a gloomy view of sexual functioning after radical vulvectomy is outlined.[2-6]

In an overview on sexual difficulties in gynaecological cancer patients, Andersen[7] stated that after radical vulvectomy as many as 50% to 90% of the women may stop all sexual activity. However, there is one retrospective study on sexual functioning after radical vulvectomy in which 8 of the 10 participating couples accomplished complete or partial sexual rehabilitation and were satisfied with their sexual relationship.[8]

To clarify this remarkable difference in outcome between existing studies and to avoid the limitations of the retrospective research design, i.e., absence of pre-treatment observations, repeated assessment and comparison groups, a longitudinal study of sexual functioning was started when patients with carcinoma of the vulva were admitted to the hospital but before they started treatment. This study was continued for 2 years post-treatment. Sexual functioning was made operational in terms of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, and the perception of genital sensations of sexual arousal. A comparison was made with an age-matched nonpatient control group. Also, physical variables (the perception of physical conditional hindrance, negative sensations during sexual arousal and genital sensitivity) were measured. The impact of these physical variables on sexual functioning is

discussed. This study forms part of a more extensive research project on the effect of gynaecological cancer treatment on sexual behaviour.

6.4.2 Methods

Women with carcinoma of the vulva, together with their partners, were invited to participate in the research project, when hospitalized but before treatment. Inclusion criteria included the following: (1) participants were younger than 70 years; and (2) absence of pre-treatment psychiatric or somatic disorders in one or both partners that might interfere with their sexual relationship.

6.4.2.1 Design

The voluntary nature of participation was stressed and it was made explicitly clear that it would be possible to withdraw from the research programme at any time.

Assessments took place on admission, before treatment, and at 6, 12, and 24 months post-treatment. The 6-month period was chosen because it was considered long enough for the couples to have resumed normal life and for the social and other relevant problems resulting from the treatment to have manifested themselves. The 12-month period was chosen because no more psychosexual changes induced by the disease or its treatment were expected after this period.[9] To verify this contention, and to study the long-term evolvement of sexual functioning, a 24-month assessment was added to the study. In addition, a single assessment of a group of age matched healthy women was also provided for comparison on the standardized measures of sexual functioning. Results were analyzed statistically by means of one way Manova repeated measurements procedures.[10]

In this study, sexual functioning is defined as a rather broad construct that covers the following aspects of sexuality: current sexual behaviour (overt manifestations of sexual behaviour); libido or sexual motivation (the wish for and appreciation of sexual interaction); sexual (dis)satisfaction (the emotional outcome of sexual interaction in terms of a global overall judgment) and the perception of genital symptoms of sexual arousal and orgasm (the sexual response).

To measure current sexual behaviour, sexual motivation and sexual (dis)satisfacion, the Intimate Bodily Contact Scale (IBCS) of Vennix was used.[11] The IBCS is an extensive self-report questionnaire which contains 22 subscales, covering various aspects of sexual functioning. The scales are standardized for heterosexual Dutch men and women separately and the internal consistency is generally high. The IBCS is based on Rotter's theory on social learning and assesses people's expectancies about the outcomes of sexual interaction. Scores on the IBCS are therefore expressed in terms of "expectancy percentages,"; e.g., a score of 80.0 on IBCS-1 (frequency of intimacy) means that the patient's expectation that feelings of intimacy will be experienced during lovemaking is 80%. The score range of the subscales of the IBCS, except the general satisfaction with sexual interaction scale (GSS), run from 0 to 100. The GSS score range runs from 5 to 34 and is no expectancy percentage. In order to avoid overburdening the patients with the complete IBCS, only a limited number of subscales were used.

To measure sexual arousability and the perception of genital symptoms of sexual

arousal during lovemaking the Groningen Arousability Scale (GAS) was developed. The GAS is a self-report questionnaire based upon the work of Masters and Johnson[12], Kaplan[13] and Newcomb and Bentler[14] and contains four subscales: (1) perception of positive genital sensations during sexual arousal, GSSUM (eight items; $\alpha = .83$); (2) perception of positive genital sensations during orgasm, OSSUM (four items; $\alpha = .78$); (3) perception of negative genital sensations during sexual arousal and orgasm and especially during coitus, NEGSUM (five items; $\alpha = .67$); and (4) the ability to induce sexual arousal and orgasm, CAPSUM (six items; $\alpha = .79$).

Also included in this study was "the perception of physical conditional hindrance" (IBCS 13). This subscale (six items; $\alpha = .87$) measures general mood disturbances which may interfere with the motivation for and outcome of sexual interaction, e.g., feelings of tiredness and fatigue.

Genital sensivity was measured by means of an electric stimulus and expressed in terms of a Genital Sensivity Threshold (GST), i.e., the smallest intensity of an electric current, expressed in milliamperes, which, at a certain frequency and duration of the stimulus, evokes a prickly sensation. This method of measuring sensitivity was specially designed for this study and further details of it have been published elsewhere.[15] Each assessment of the subject included a visit to the gynaecologist to detect recurrence of the disease or the presence of other diseases which might interfere with sexual functioning. Before the treatment the questionnaires were given to the participants next to the introduction of the investigation. Later on questionnaires were sent to them by mail and turned in during a subsequent visit to the gynaecologist.

6.4.2 Subjects

Patient Population. Thirteen women and their partners were invited to participate in the research project. None of these women or their partners had a history of psychiatric or somatic disorder that might interfere with their sexual relationship. Three couples did not feel able to participate because of emotional reasons. Therefore, ten couples participated in the project. Eight women were to undergo a radical vulvectomy with bilateral groin dissection. Vulvar reconstruction (bilateral gracilis myocutaneous graft) was performed in one of them. For two women, surgery could be limited to partial vulvectomy involving removal of the clitoris. Four women received additional radiation therapy. All participants were involved in a stable heterosexual relationship at the time of the study. On admission, all of the women had physical complaints which may interfere with sexual functioning. Seven women complained of itching, four women of dyspareunia and three women of excessive vaginal discharge. The estimated duration of these complaints varied from 1 to 72 months. Five women were postmenopausal, one of them had received estrogen substitution. Furthermore, on admission estrogen substitution was started in two women because of additional radiation therapy.

At 1-year post-treatment, one woman was found to have a fistula in the operated area and needed several subsequent operations from which she finally recovered. One woman, with stenosis of the introitus vaginae, underwent additional plastic surgery. Another women, with stenosis of the introitus vaginae, was not motivated for

Table 1 Age, Diagnosis and treatment of the Respondents

Subject	Age	Initial diagnosis	Primary treatment
1	40	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection and radiotherapy
2	49	c/a vulva in situ	Partial vulvectomy without lymph node dissection. Clitoris removed
3	63	c/a vulva stage II	Radical vulvectomy with bilateral inguinal lymph node dissection
4	69	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection and radiotherapy
5	57	c/a vulva stage II	Radical vulvectomy with bilateral inguinal lymph node dissection and radiotherapy
6	44	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection and radiotherapy
7	47	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection
8	37	malignant melanoma (Clarck III)	Partial vulvectomy with ipsilateral lymph node dissection. Clitoris removed
9	49	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection
10	38	c/a vulva stage I	Radical vulvectomy with bilateral inguinal lymph node dissection. Bilateral gracilis myocutaneous graft for vulvar reconstruction

reconstruction. In three other cases the follow-up had to be discontinued in the second year post-treatment because of recurrence of the disease; two of these women died. The final sample then, comprised of seven women and their partners. The mean age of the women was 49 years (range, 37 to 60 years; Table 1). Data on the partners will be reported on in another article.

The control/healthy population. For this group (n = 24) the same exclusion criteria were used as for the patient population. Most women in this group were regular visitors of the clinic for contraception or were contacted by advertisement.

6.4.3 Results

The development, over time, of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, perception of genital symptoms of sexual arousal and additional somatic variables is presented in Table 2, 3 and 4. Those tables include the mean values, with standard deviation, of an age-matched nonpatient control group (mean age, 46 years; range, 37 to 52 years). Multivariate repeated measurement analysis of variance revealed some trends (i.e., a level of significance close to

.10), but no real significant time effect. However, since the sample size is very modest and therefore the chance of a B-error quite large, the results will be discussed in detail but with reserve toward the conclusions.

A comparison between the first assessment and 6 months after treatment revealed a decrease in current sexual behaviour and sexual motivation as far as frequency and appreciation of arousal and frequency and appreciation of arousal-inducing behaviour are concerned (Table 2).

Table 2 Group means on Current Sexual Behaviour and Motivation for Sexual Interaction

	Initial	6-Month	1-Year	2-Year	Control Group (+SD)
Current Sexual Behaviour					
Frequency of Intimacy (IBCS1)*	71.9	73.3	86.7	83.3	91.3 (15.6)
Frequency of Intimacy-Inducing-Behaviour (IBCS19)*	64.5	68.1	72.5	72.9	63.7 (18.4)
Frequency of Arousal (IBCS2)*	68.0	45.8	65.1	63.9	73.2 (17.2)
Frequency of Arousal-Inducing-Behaviour (IBCS20)*	56.7	47.9	60.0	64.3	60.3 (24.9)
Sexual motivation (libido)					
Appreciation of Intimacy (IBCS7)*	90.6	83.3	90.0	91.7	89.9 (9.0)
Appreciation of Intimacy-Inducing-Behaviour (IBCS8)*	81.6	65.6	84.4	84.4	81.6 (10.5)
Appreciation of Arousal (IBCS21)*	93.5	78.3	87.2	81.5	84.3 (8.6)
Appreciation of Arousal-Inducing-Behaviour (IBCS22)*	73.2	57.9	67.1	66.7	67.4 (19.8)

IBCS: intimate bodily contact scale.
* mean score (range 0 to 100%).

The other aspects of current sexual behaviour and sexual motivation also varied, although to a lesser degree. One year after the treatment, frequency and appreciation of arousal and frequency and appreciation of arousal-inducing-behaviour had, more or less, reestablished themselves at pre-treatment level. In terms of coital activity, 12 months after the treatment 7 couples were having regular intercourse again. Fifty percent of the women regained capacity for orgasm. This situation remained the same during the second year of post-treatment.

Table 3 Group means on the Perception of Genital Symptoms of Sexual Arousal and Sexual (Dis)satisfaction

	Initial	6-Month	1-Year	2-Year	Control Group Sexual Response (+SD)
Genital Symptoms of Sexual Arousal					
Positive Genital Sensations during Arousal (GSSUM)*	51.2	25.2	36.3	40.7	60.8 (17.8)
Positive Genital Sensations during Orgasm (OSSUM)*	70.8	44.4	41.6	44.4	76.3 (15.8)
Ability to induce sexual arousal and orgasm (CAPSUM)*	45.2	29.1	31.1	33.3	62.6 (14.8)
Sexual (Dis)satisfaction					
General Satisfaction with Sexual Interaction (GSS)**	32.0	27.0	26.2	27.0	29.9 (3.3)
Relation Sexual Dissatisfaction (IBCS5)*	10.6	18.0	7.0	8.3	21.1 (26.5)

IBCS: intimate bodily contact scale.
* mean score (range 0 to 100%).
** mean score (range 5 to 34).

The ability to induce sexual arousal and orgasm and the perception of positive genital sensations during sexual arousal and orgasm was seriously disturbed 6 months after the treatment with no recovery taking place over the next 1.5 years, as far as the perception of positive genital sensations during orgasm and the ability to induce sexual arousal and orgasm are concerned (Table 3). Positive genital sensations during arousal clearly tend to reestablish during the second year of post-treatment.

The general satisfaction with sexual interaction with the partner hardly changed during the 2-year observation period (Table 3). However, when analyzed separately, a temporary increase in relational sexual disatisfaction was observed 6 months after the treatment.

With regard to genital sensivity, a threefold increase in the GST was measured 6 months after the treatment with a 30% recovery rate over the next 1.5 years (Table 4). A similar increase was observed in the perception of negative sensations during sexual arousal and orgasm 6 months after the treatment, with a 40% reduction rate in negative sensations taking place after 1.5 years. The perception of physical conditional hindrance showed a slight increase 6 months after treatment.

Table 4 Group means on Additional Somatic Variables

	Initial	6-Month	1-Year	2-Year	Control Group (+SD)
Additional Somatic Variables					
Genital Sensitivity Treshold (GST)***	11.6	32.1	25.9	22.6	12.3 (6.9)
Negative Sensations during Arousal (NEGSUM)*	12.5	41.6	37.5	25.0	12.8 (13.0)
Physical Conditional Hindrance (IBCS13)*	32.8	37.5	32.5	33.3	31.0 (17.4)

IBCS: intimate bodily contact scale.
* mean score (range 0 to 100%).
*** mean score (in mA).

6.4.4 Discussion

In this longitudinal study of psychosexual functioning after radical vulvectomy for invasive cancer, the primary assessment was conducted during admission but before treatment. This is an exceedingly difficult time for patients and their partners. Nevertheless, 10 of 13 couples agreed to participate in the study.

The final sample, 2 years post-treatment, was comprised of 7 women and their partners. We decided to publish the results of this small sample because of the originality of the study. There has been minimal study of the sexual course of these patients and no prospective evaluation of their psychosexual outcome. Since currently there is discussion among gynaecological surgeons regarding the magnitude of radical surgery required for adequate treatment,[16-18] data of this type should be useful in evaluating the sexual functioning morbidity associated with vulvar surgery.[19]

Cancer of the vulva is associated with long-term symptoms before diagnosis.[20] These symptoms may have already affected sexual functioning.[7,21] However, there was no difference between the sexual functioning of the age-matched nonpatient control group and the patient group before their treatment despite the patient group's multiple physical complaints, e.g., itching, dyspareunia, and vaginal discharge. It could be suggested that the long-term nature of the symptoms may have mitigated their impact on sexual functioning. However, severe damage to sexuality could be confirmed, particularly at the 6-month assessment. Nevertheless, in spite of a persistent, marked, deterioration in the perception of genital symptoms of sexual arousal, all women who were sexually active before treatment had resumed their sexual activities within 1-year post-treatment. In comparison with the pre-treatment situation and the control group, no clear difference in general satisfaction with sexual interaction with the partner was found. Obviously, participation in the research project may include a rehabilitative effect and this could explain these results (i.e., the Hawthorne effect). However, in a retrospective pilot study,[8] 8 of the 10 partici-

pating couples also accomplished complete or partial sexual rehabilitation and were also satisfied with their sexual relationship.

Furthermore, the patient populations in the retrospective study and in this prospective study were not particularly younger than patient populations in the previous literature in the area.[2-6] Patients in all of these studies have the same disease, similar mutilating surgery with or without additional radiation therapy, and are of the same average age. In these circumstances it might be suggested that psychosocial factors play a large part in sexual rehabilitation. For example, in a survey of postvulvectomy patients, Stellman et al.[4] got the impression that "loss of sexual functioning was related more to psychological factors than to anatomic dysfunction". Similarly, Weijmar Schultz et al.[8] interviewed 10 postvulvectomy patients and their partners and stated that "the motivation for sexual interaction, closely related to the extent of mutual affection, might be more important for sexual rehabilitation than any physical restriction imposed by the surgery."

The limited importance of physical variables for sexual rehabilitation may also be inferred from the course of the evolution of the perception of genital symptoms of sexual arousal: genital sensitivity and genital sensations during arousal increase and fewer negative sensations are reported, but in spite of this an improvement in the ability to induce sexual arousal and orgasm and the perception of positive sensations during orgasm fails to appear. Apparently, more is needed to change the perception of genital symptoms of sexual arousal than the regeneration of peripheral nerve fibers and a reduction of negative sensations during arousal. Also, in spite of the physical damage and a persisting poor perception of genital symptoms of sexual arousal throughout the observation period, the women reported being satisfied with their sexual life with their partner. In other words, neither physical damage nor the perception of genital symptoms of sexual arousal are valid indicators of sexual satisfaction with a partner.

These data confirm the validity of former descriptions on this subject. Andersen et al.,[22] in a retrospective survey on sexual, marital, and psychological adjustment after treatment of in situ vulvar cancer, found that despite excitement and orgasm difficulties sexual activity is maintained, women do not lose their desire for sexual activity, and they regard their relationships as satisfactory. Schover et al.,[23] in a prospective study of women treated for invasive cervical cancer, observed that women's sexual satisfaction, capacity for orgasm, and frequency of masturbation remained stable, whereas frequency of sexual activity with a partner and range of sexual practices decreased significantly by 1 year. All of these data suggest that a woman's motivation for, and satisfaction with sexual interaction with her partner may not be limited to the experience of sexual arousal. A whole range of other emotions may be involved.[24,25]

Remarkable is the difference in relational sexual dissatisfaction of the patient populations' assessment and that of the control group throughout the observation period. It is possible that the experimental group, due to their condition, felt excessively dependent upon their partners. The temporary increase in relational sexual dissatisfaction 6 months post-treatment possibly reflects a difference in adaptation between the patient and her partner.[26] When, 6 months post-treatment, the partner seems to be able and willing to restore sexual activities, the patient is not. This might

cause some mutual irritation and thereby relational sexual dissatisfaction. The decrease in relational sexual dissatisfaction 1 year post-treatment demonstrates that most couples are able to cope with these "starting problems."

After treatment for carcinoma of the vulva 50% of the women in this small sample reported being able to achieve orgasm. All of the women respondents mentioned returning sensitivity in the area of the clitoris. This was confirmed by measuring genital sensitivity.

It can be concluded that after the treatment for carcinoma of the vulva, in spite of many problems, sexual activities do not stop for the majority of couples. Persisting poor sexual response does not prevent the women from expressing satisfaction regarding the sexual interaction with their partner. It has been suggested that psychological and social variables may be more important for sexual rehabilitation than physical variables. Therefore, psycho-social issues may prove to be a promising focus of intervention. Because sexual activities do not cease, such interventions may be particularly beneficial in the first year after treatment.

REFERENCES

1. MAGES, N.L. & MENDELSOHN, G.A. (1979) Effect of cancer on patient's life: a personological approach. In: G.C. Stone, F. Cohen & N.E. Adler (Eds.) Health Psychology. San Fransisco, Jossey-Bass.
2. YEW CHEONG CHOV (1982) Invasive squamous carcinoma of the vulva in young patients. Gynecologic Oncology, 13, pp. 158-164.
3. ANDERSEN, B.L. & HACKER, N.F. (1983) Psychosexual adjustment of gynecologic oncology patients: a proposed model for future investigation. Gynecologic Oncology, 15, pp 214-223.
4. STELLMAN, R.E., GOODWIN, J.M., ROBINSON, J., DANSAH, D. & HILGERS, R.D. (1984) Psychological effects of vulvectomy. Psychosomatics, 25, pp. 779-783.
5. ANDREASSON, B., MOTH, J., JENSEN, S.B. & BOCK, J.E. (1986) Sexual function and somatopsychic reactions in vulvectomy-operated women and their partners. Acta Obstetricia et Gynecologica Scandinavia, 65, pp. 7-10.
6. TAMBURINI, M., FILIBERTI, A., VENTAFRIDDA, V. & DEPALO, G. (1986) Quality of life and psychological state after radical vulvectomy. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 263-269.
7. ANDERSEN, B.L. (1986) Sexual difficulties for women following cancer treatment, In:Women with cancer, psychological perspectives. New York, Springer Verlag, pp. 257-288.
8. WEIJMAR SCHULTZ, W.C.M., WIJMA, K., WIEL, H.B.M. VAN DE, BOUMA, J. & JANSSENS, J. (1986) Sexual rehabilitation of radical vulvectomy patients. A pilot study. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 119-126.
9. MORRIS, F., GREER, H.S. & WHITE, P. (1986) Psychological and social adjustment to mastectomy. Cancer, 40, pp. 2381-2387.
10. NORUSIS, M.J. (1988) SPSS/PC+ Advanced Statistics. Chicago, SPSS Inc.
11. VENNIX, P. (1983) De ILKS gedachte. Zeist, NISSO.
12. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
13. KAPLAN, H.S. (1979) Disorders of Sexual Desire. New York, Brunner/Mazel.

14. NEWCOMB, M. & BENTLER, P. (1983) Dimensions of subjective female orgasmic responsiveness. Journal of Consulting and Clinical Psychology, 44, pp. 862-877.
15. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, KLATTER, J.A., STURM, B.E. & NAUTA, J. (1988) Genital sensivity for electric stimuli, theoretical and practical implications. Archives of Sexual Behavior, 18, pp. 87-95.
16. HACKER, N.F., BEREK, J.S., LAGASSE, L.D., NIEBERG, R.K. & LEUCHTER, R.S. (1984) Individualization of treatment for stage I squamous cell vulvar carcinoma. Obstetrics and Gynecology, 63, pp. 155-162.
17. BOICE, C.R., SERAJ, I.B., THRASHER, T. & KING, A. (1984) Microinvasive squamous carcinoma of the vulva: Present status and reassessment. Gynecologic Oncology, 18, pp. 71-76.
18. DISAIA, P.J. (1985) Management of early invasive vulvar carcinoma. In: A. Onnis & T. Massino (Eds.) New Surgical Trends and Integrated Therapies in Endometrial, Vulvar, Trophoblastic Neoplasias. Actuality of Surgical Malignancies. Padua, La Garangola, pp. 134-142.
19. ANDERSEN, B.L. (1984) Psychological aspects of gynaecological cancer. In: A. Broome & L. Wallace (Eds.) Psychology and Gynaecological Problems. New York, Tavistock Publications, pp. 117-141.
20. BLAUSTEIN, A. (1988) Pathology of the female genital tract. New York, Springer Verlag.
21. MANTELL, J.E. (1983) The psychosocial and physiological effects of invasive gynecologic cancers on female sexuality. In: L. Dennerstein & M. De Senarclens (Eds.) The young women: psychosomatic aspects of Obstetrics and Gynecology. Amsterdam, Exerpta Medica, pp. 398-408.
22. ANDERSEN, B.L., TURNQUIST, D., LAPOLLA, J. & TURNER, D. (1988) Sexual functioning after treatment of in situ vulvar cancer: preliminary report. Obstetrics and Gynecology, 71, pp. 15-19.
23. SCHOVER, L.R., FIFE, M. & GERSHENSON, D.M. (1989) Sexual dysfunction and treatment for early stage cervical cancer. Cancer, 63, pp. 204-212.
24. HITE, S. (1976) The Hite Report. New York, Macmillan.
25. LEIBER, L, PLUMB, M.M., GERSTENZANG, M.L. & HOLLAND, J. (1976) The communication of affection between cancer patients and their spouses. Psychosomatic Medicine, 38, pp. 379-389.
26. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecologic Oncology, 9, pp. 275-281.

6.5 Sexual functioning of women treated for cancer of the vulva*

Summary

In this article sexual functioning of 7 women treated for cancer of the vulva 12 months post treatment is described. A detailed assessment of current sexual functioning was carried out using both interviews and self-report questionnaires for data collection. The results make clear that according to the participant's point of

* H.B.M. van de Wiel, W.C.M. Weijmar Schultz, A. Hallensleben, F.G. Thurkow, J. Bouma & A.C. Verhoeven (1990) Sexual and Marital Therapy, 5, pp. 73-82

view rather dramatic changes in sexual life occurred because of the cancer and its treatment. However, if we compare the data of the participants with data from an age-matched control group, no important differences could be traced on the main aspects of sexual functioning, i.e. sexual satisfaction, sexual behaviour and sexual motivation. Only remarkable differences in experienced sexual arousal and orgasm could be noticed. It is therefore hypothesized that sexual rehabilitation itself is guided on a higher level by a more general striving for balance in the relationship. This means that interventions to prevent or reduce sexual problems after gynaecological cancer treatment could best be directed not only to the patient but to the partner as well.

6.5.1 Introduction

Cancer is often looked upon as a breaking point in life because it leads to considerable changes in how people regard themselves and their future. Moreover, treatment frequently results in irreversible physical damage which in turn brings on changes in patterns of behaviour.[1] One of these patterns of behaviour involves sexual functioning.

Invasive cancer of the vulva, nowadays accounting for approximately 8 percent of all gynaecological cancers, means confrontation with severely disfiguring surgery: vulvectomy. This surgery implies the loss of labia majora and minora, removal of the clitoris, mons veneris, surrounding tissues and frequently extensive lymph node dissection. In advanced disease additional radiation therapy is given. It is therefore very likely that sexual functions will be affected as a result of disease and treatment.

Up till now only brief descriptions of the psychosexual outcome of these patients are available.[2-6] The few results produced are limited in their value, however, because they are based on largely descriptive and retrospective studies in which no controlgroups were included. This latter is especially noteworthy because in studies on non-patient populations also a rather large incidence of sexual problems is being reported.[7-9] This means that some doubts can be raised about previous studies on the sexual consequences of vulvectomy, especially with regard to their internal validity, i.e. the question whether these sexual problems did not already exist before onset of the disease or treatment. Another point of critique is on the rather narrow way sexual functioning usually is being defined. Sexual functioning is usually operationalized as "frequency of intercourse" or measurements of "general sexual satisfaction", thereby referring to a rather limited sample of human sexual behaviour.

The current investigation was designed to describe the sexual functioning of women treated for cancer of the vulva, at 12 months post-treatment. A detailed assessment of current sexual behaviour, motivation for sexual interaction, sexual response and satisfaction with sexual life was carried out using both interviews and self-report questionnaires for data collection. An age-matched control group was added to investigate the hypothesis that vulvectomy patients have a more problematic sexlife than other women of comparable age.

6.5.2 Method

6.5.2.1 Population

In the period of 1984 to 1987, 7 women treated for carcinoma of the vulva in the Department of Gynaecology of the University Hospital Groningen (the Netherlands) participated in this study. All participants had a steady relationship, 6 of them were married for longer than 15 years. The mean age of these patients at the time of the treatment was 49 years (range: 37-60).

6.5.2.2 Definition of sexual functioning

In this study sexual functioning is defined as a rather broad construct that covers the following aspects of sexuality:

- current sexual behaviour: overt manifestations of sexual activity;
- the sexual response cycle: the anatomic and physiologic aspects of human sexual responding as defined by Masters and Johnson[10];
- libido or sexual motivation: the wish for sexual interaction;
- sexual (dis)satisfaction: the emotional outcome of sexual interactions, in terms of a global overall judgment.

6.5.2.3 Procedure

During hospitalisation but before actual treatment the patients and their partners were invited to participate in a prospective study on the consequences of their treatment on sexual functioning. The voluntary character of participation was stressed and it was made explicitly clear that the possibility to withdraw would remain open at all times. Assessments took place before treatment, 6, 12 and 24 months after treatment. In this study the results of the assessment of the patients 12 months after treatment will be discussed. This period of time is chosen because from other psychosexual research on gynaecological cancer patients, it appeared that after this period no other psychosexual changes induced by the disease or treatment are to be expected anymore.[11-12]

6.5.2.4 Data collection

Data on sexual functioning 12 months after treatment were collected in two different ways:

1) by semi-structured interview, and
2) by self-report questionnaires.

By combining both methods of data collection the study could be given a more firm methodological basis and complementary information could be collected.

The interview Each patient was interviewed by a female psychologists (A.H.). The interviews took place in the hospital and lasted about three quarters of an hour to one hour and a half. All participants gave their permission in advance for the interview to be tape-recorded. The psychologist was unaquainted with the participant and ignorant to detailed aspects of the participant's disease and treatment.

In the interviews special notice was given to subjective changes in the following aspects of sexual functioning:

- sexual activity
- feelings of sexual arousal and orgasm
- sexual motivation
- sexual satisfaction.

To score the interviews, content analysis was performed, i.e. analytic categories were constructed, in which the participant's responses were scored on a ordinal level by the interviewer and, independently, by another female psychologist (F.G.T.), using the original taperecordings and fully written-out protocols of the interviews. All the answers to each variable were scored on a 5 point-scale, in order to make a quantitative presentation of the data. The interrates reliability scores of the interview procedure are depicted in Table I.

Table I Interraters reliability scores from the semi-structured interviews (5 point scales)

	Cohen's Kappa	Spearman's Correlation
- changes in sexual satisfaction	.57	.86 **
- changes in sexual behaviour	.12	.57 *
- changes in sexual motivation	.22	.53 *
- changes in sexual arousal	.41	.87 **
- changes in orgasm	.53	.94 **

* $p<.05$
** $p<.001$

The self-report questionnaires In this study two self-report questionnaires were used both consisting of a large number of multiple choice items.

The first questionnaire is the "Intimate Bodily Contact Scale" (IBCS) of Vennix.[13] The IBCS is a rather extensive questionnaire, based on Rotter's theory on social learning,[14] that contains 22 subscales, together covering a large number of aspects of sexual functioning in a very detailed manner. The subscales have separate norms for men and women and the internal consistency of the subscales is generally high. The reliability coefficients of the subscales used in this study are depicted in table II.

The second self-report questionnaire used in this study is the "Groningen Arousability Scale" (GAS). The GAS is a specially for this research project designed questionnaire containing 4 subscales, focussing on genital sensations during arousal and capacity to induce sexual arousal and orgasm. Reliability co-efficients of the subscales of the GAS are also depicted in table II. Population norms for the female population are available. In order to avoid overburdening the patients, from the IBCS and GAS only a limited number of subscales was used.

Table II Reliability scores of the subscales of the IBCS and GAS

	subscale	
- general sexual dissatisfaction	IBCS - 6	.91
- frequency of sexual arousal-inducing-behaviour	IBCS - 20	.81
- appreciation of sexual arousal	IBCS - 8	.85
- appreciation of sexual arousal-inducing-behaviour	IBCS - 22	.87
- frequency of sexual arousal	IBCS - 2	.89
- frequency of genital sensation during sexual arousal	GAS - 1	.84
- frequency of orgastic sensations	GAS - 2	.78

6.5.2.5 Design

Putting the two methods of data gathering together leads to an operationalization, as is depicted in Table III.

To test the hypothesis that vulvectomy patients have a more problematic sexlife due to their treatment than other women of comparable age, two different designs were used, each corresponding with the method of data collection. A between group design was used to compare the data obtained with the self-report questionnaires. Mean scores of the experimental population were compared with mean scores of two different non-patient control populations:

- for the IBCS a special age-matched control group could be made, using the original data of Vennix[13]
- for the GAS only a non-age-matched control group was available.

A time controlled retrospective within subject design was used to analyze the data obtained from the interviews. This means that patients were asked to compare their current situation with the situation before confrontation with the diagnosis one year ago.

Table III Operationalization scheme of sexual functioning (i.c. sexual (dis)satisfaction, sexual motivation, sexual behaviour and sexual response by means of self-report questionnaires as well as semi- structured interviews

variable name	questionnaire (subscales)	interview (question about)
SEXUAL (DIS)SATISFACTION:		
- sexual dissatisfaction	IBCS - 6	changes in overall sexual satisfaction
SEXUAL BEHAVIOUR:		
- current sexual behaviour	IBCS - 20	changes in behaviour sexual behaviour
SEXUAL MOTIVATION:		
- appreciation of sexual arousal	IBCS - 8	changes in sexual
- appreciation of sexual behaviour	IBCS - 22	motivation
SEXUAL RESPONSE:		
- experienced sexual arousal (central)	IBCS - 2	changes in sexual arousal
- experienced sexual arousal (periphere)	GAS - 1	
- experienced feelings of orgasm	GAS - 2	changes in orgasm

6.5.2.6 Statistics

Differences between the experimental and the control groups were not tested on statistical significance because of the limited number of observations. Rather the comparison between the experimental and controlgroup gives an indication of how to interpretate experimental data.

6.5.3 Results

The data from the interviews (table IV) show that carcinoma of the vulva has disturbing consequences for most parts of sexual functioning. Four out of 6 participants reported negative changes in sexual satisfaction, of which half were moderate and half were severe negative changes.

With regard to sexual behaviour it appeared that 4 out of 7 patients reported severe negative change and 1 moderate negative change, which means that, at least on behavioural level, a strong reduction in sexual functioning did occur. Despite these changes, however, 1 year after treatment, 6 out of 7 patients are sexually active again, including sexual intercourse (1 patient did not have sexual intercourse before the operation either).

Sexual motivation, on the contrary seems to be less affected. Three out of 6 participants report a moderate reduction in libido, even despite the fact that they all reported severe negative changes in sexual arousal, and 5 out of 6 (1 is unknown) mentioned a strong reduction in experiencing orgasm.

When we compare the participant's data, obtained by means of self-report questionnaires, with those of an age-matched controlgroup (table V), it appears that

Table IV Changes in sexual functioning one year after treatment of vulvar cancer (n=7) as reported in the interviews

	=	-	- -	?
- changes in sexual (dis)satisfaction	2	2	2	1
- changes in sexual behaviour	1	2	4	0
- changes in sexual motivation	3	3	0	1
- changes in experienced arousal	0	0	7	0
- changes in experienced orgasm	1	1	4	1

= no change
- some negative change
- - severe negative change

Table V Scores (mean and standard deviation) of the subscales of the IBCS and the GAS for the experimental population (EP, n=7) and an age-matched control group (CP, n=24)

	EP (x/s)	CP (x/s)
IBCS - 2	60.4/ 9.5	73.2/17.2
IBCS - 20	59.8/29.2	60.3/20.5
IBCS - 8	82.0/12.1	78.0/10.5
IBCS - 22	62.5/26.2	67.4/19.8
IBCS - 6	16.7/11.5	13.9/14.0
GAS - 1	32.4/22.9	62.2/18.0
GAS - 2	30.5/26.7	76.6/15.5

remarkable differences only exist on those variables which represent the sexual response: experienced central and peripheral arousal and orgasm.

However, with regard to sexual dissatisfaction, sexual behaviour and sexual motivation, no remarkable differences between the patient and the control population seem to occur 1 year after treatment.

6.5.4 Discussion

Vulvectomy is a mutilating operation and patients are confronted daily with the aftereffects of their treatment. This is especially the case with regard to areas as femininity and sexuality or as one of our participants stated:" You don't feel a woman anymore, you feel damaged. Your body has been violated, you don't feel anything there anymore and you really have to force yourself to have sex".

Based on the results of the interviews and questionnaires it seems clear that according to the participant's point of view rather dramatic changes in sexual life occurred because of the cancer and its treatment. However, if we compare the data of

the participants with data from an age-matched control group, many of these differences are put in another perpective. In fact, with regard to the main aspects of sexual functioning, i.e. sexual satisfaction, sexual behaviour and sexual motivation hardly any differences between the two groups do occur. Only remarkable differences in experienced sexual arousal and orgasm can be noticed.

An explanation for this remarkable phenomenon could be that the negative impact of vulvacarcinoma and its treatment is only large for those women who highly value central and peripheral aspects of sexual arousal and orgasm. For others, the meaning of sexuality seems to be located elsewhere. Our impression of the interviews is that the meaning of sexuality and wish for sexual interaction is mainly determined by the desire to please the partner and to get more harmony in the relation. A fragment from one of the interviews might illustrate this: "Well, I really have to force myself to it. I think to myself: come on, you have to do something for someone else now again. I don't feel like it anymore".

Although this reaction might seem to be a little bit strange, given the dramatic situation of these mutilated women, a quite logical explanation can be found in the Equity Theory.[16] According to this theory human relations are "fair exchange" relations. Is the exchange balance disturbed then this leads to stressfull feelings, forcing the individuals to restore the original balance. A woman having experienced a lot of emotional support from her partner in the period before, during and after the treatment following the diagnosis cancer of the vulva, will try to restore the balance by giving her partner what she thinks he wants, in spite of her own problems. Again this might best be illustrated by a fragment from one of the interviews: "Because you feel how he gives you his love, you want to give it back to him also. So you want to be there for him also, one way or the other. I have always tried to do my utmost for that".

Similar results were reported by Weijmar Schultz et al.[4]: "For some of our couples sexual intercourse took place only for the sake of the male partner, while it did not appeal to the female partner at all: the patient apparently resumed sexual activity because of the affection for her partner. It is also possible that fear of losing the partner plays an important role". In this current study again the affection for the partner, the wish to do something in return, but also the fear of losing the partner seem to play an important role in the motivation for the actual sexual behaviour. The part of the partner therefore does not seem to be a very sympathetic one. It looks as if he "must have his share" as his wife has gone through all kinds of dreadful experiences. Yet a more differentiated approach is possible. His wish to have sexual intercourse could well be (at least partly) a way to support his wife and a proof of her being still attractive and lovable after all. A man could also feel the pressure of social norms about sexual intercourse. Also it could be his way to reduce her stress in the light of the Equity Theory.[15] Moreover what would it mean for women to have a husband who does not behave as a "healthy man" anymore and does not want sexual intercourse? This in fact might increase feelings of worthlessness or as one woman stated: "My husband does not want to have sex with me anymore. He says you have suffered enough. When my husband says I don't want anymore, what can I say?.... I am often grieving. Then I think no one cares about me anymore and I get very depressed".

Although the results of this study can have a limited value only because of the small number of participants involved, it can be cautiously concluded that treatment of vulvacarcinoma by vulvectomy results in deterioration of important aspects of sexual functioning but that on other important aspects adaptation takes place and that this process of sexual rehabilitation is guided by a more general striving for balance in the relationship.

The implication of these conclusions for clinical practice is that, as we stated earlier),[16] interventions to prevent or reduce sexual problems after gynaecological cancer treatment could best be directed not only to the patient but to the partner as well.

REFERENCES

1. MAGES, N.L. & MENDELSOHN, G.A. (1979) Effect of cancer on patient's life: a personological approach. In: G.C. Stone, F. Cohen & N.E. Adler. Health Psychology. San Francisco, Jossey-Bass, pp. 22-284.
2. ANDREASSON, B., MOTH, J., JENSEN, S.B. & BOCK, J.E. (1986) Sexual function and somatopsychic reactions in vulvectomy-operated women and their partners. Acta Obstetricia et Gynecologica Scandinavia, 65, pp. 7-10.
3. TAMBURINI, M., FILIBERTI, A., VENTAFRIDDA, V. & DEPALO, G. (1986) Quality of life and psychological state after radical vulvectomy. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 263-269.
4. WEIJMAR SCHULTZ, W.C.M., WIJMA, K., WIEL, H.B.M. VAN DE, BOUMA, J. & JANSSENS, J. (1986) Sexual Rehabilitation of radical vulvectomy patients. A pilot study. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 119-127.
5. ANDERSEN, B.L. & HACKER, N.F. (1983) Psychosexual adjustment of gynecologic oncology patients: a proposed model for future investigation. Gynecologic Oncology, 15, pp. 214-223.
6. YEW CHEONG CHOV. (1982) Invasive squamous carcinoma of the vulva in young patients. Gynecologic Oncology, 13, pp. 158-164.
7. VENNIX, P. (1989) Seks en sekse. Delft, Eburon.
8. FRENKEN, J. (1976) Afkeer van seksualiteit. Deventer, Van Loghum Slaterus.
9. MASTERS, W.H. & JOHNSON, V.E. (1970) Human sexual inadequacy. Boston, Little Brown and Company, pp. 286-287.
10. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
11. MORRIS, T., GREER, H.S. & WHITE, P. (1977) Psychological and social adjustment to mastectomy. Cancer, 40, pp. 2381-2387.
12. VINCENT, C.E., VINCENT, B., GREIS, F.C. & LINTON, E.B. Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
13. VENNIX, P. (1983) De ILKS gedachte. Zeist, NISSO.
14. ROTTER, J.P. (1954) Social learning and clinical psychology. New York, Prentice Hall.
15. WALSTER, E., WALSTER, G.W. & BERSCHEID, E. (1978) Equity: theory and research. Boston, Allyn and Bacon.
16. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURHOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecologic Oncology, 9, pp. 275-281.

6.6 Sexual functioning of partners of gynaecological oncology patients; a pilot study on involvement, support, sexuality and relationship*

Summary

In the process of coping with the physical and emotional consequences of gynaecological cancer treatment, the support of loved ones, especially an intimate partner, is of crucial importance. Little is known, however, about the problems these partners have to face during the period of treatment.

In this study 16 partners of women treated for gynaecological cancer were interviewed, 12 months post treatment, about two central themes: "involvement and support" and "sexuality and relationship". Because the generalizability of the results of this study is limited, only some cautious conclusions can be drawn. With regard to involvement and support, it appeared that many men experienced the process of providing support as a stressful process and had serious doubts about their provided support. With regard to sexuality and relationship, it appeared that these partners do have extensive sexual problems, which could not adequately be solved.

As a possible explanation for both phenomena, it is hypothesized that the disease and its treatment also poses a crisis for the partner, which leads to a regression towards a more rigid, male stereotype way of coping. This means that attention should not only be given to the patient during treatment, but also to her partner and to their communication patterns.

6.6.1 Introduction

The diagnosis and treatment of gynaecological cancer constitute a severe burden for a woman. Cancer is a life-threatening disease and because of the specific location of gynaecological cancer, mutilation and loss of the most intimate parts and functions of her body is impending. In the process of coping with her physical and emotional problems during this period of crisis, the support of loved ones, especially an intimate partner, is of crucial importance.[1-3]

For most women treated for gynaecological cancer, this support is provided sufficiently, but approximately one third of them have troubled relationships, caused by sexual problems and a lack of open communication.[3] Instead of being a central source of support for the patient, the partner might become part of the problem, having a negative effect on her recovery.[4] Thus, it is of great value to help these women and their partners to form a sound relationship.

Little is known, however, about the problems these partners have to face during the period of treatment. Although some studies mention the existence of fears, frustrations, aversion and conflicts in their attitude towards the patient[5-7] according to Leiber et al.[8] this does not lead to emotional alienation or the withdrawal of affection between the patient and partner. From the same study it appeared that the process of social support follows a pattern which is consistent with traditional sex roles;

* H.B.M. van de Wiel, W.C.M. Weijmar Schultz, J. Wouda & J. Bouma (1990) Sexual and Marital Therapy, 5, pp. 123-130.

women openly express their fears and worries while the male partners tend to suppress their needs and emotions.

Studies specifically focussing on the sexual life of spouses whose partners were treated for gynaecological cancer, could not be detected in the literature. In the above-mentioned study by Leiber et al. on patients receiving chemotherapy for advanced stage cancer and their parners, it was found that both patients and partners reported a decrease in the desire for intercourse and an increase in the desire for non-sexual physical closeness. A shift in emphasis of the motives becomes manifest, from sexual excitement to intimacy.

Given the scarcity of empirical data on these aspects of gynaecological cancer treatment, it was decided to set up a specific study as part of a larger research programme on sexual functioning after gynaecological cancer treatment, to investigate topics such as involvement, support, sexuality and relationship as experienced by the male partner during the 12-months period following their wife's treatment.

6.6.2 Methods

The partners of 24 women admitted to the University Hospital Groningen for gynaecological cancer treatment were asked to participate in this research project, of whom 16 consented (response rate of 68%).

Data were gathered by means of a semi-structured interview which was held 12 months after treatment. This period of time was chosen because other psychosexual research on (breast) cancer patients has shown that no other psychosexual changes induced by the disease or treatment are to be expected after this period.[9]

6.6.2.1 The Interviews

All participants were males. They were all interviewed by a male psychologist (H.B.M.v.d.W.).

The mean age of this population was 51 years, with a range of 33 to 70.

All participants had a long-term relationship, which means that they were married or were living together for at least 5 years.

The interviews took place at the hospital and lasted for about 3 quarters of an hour. All the participants gave their permission in advance for the interview to be taperecorded. The psychologist was unaquainted with the patient and ignorant of detailed aspects of the patient's disease and treatment. To score the interviews, content analysis was performed, i.e. analytical categories were constructed, in which the participants' responses were scored on an ordinal level by another psychologist (J.W.), using the original tape recordings and fully written-out protocols of the interviews. All the answers to each variable were scored on a 3-point scale, in order to make a quantitative presentation of the data.

6.6.2.2 Themes

The topics discussed in the interviews could be clustered around two central themes: "involvement and support" and "sexuality and relationship". The following 11 topics, classified around these 2 themes, were discussed:

Involvement and support
- feelings about the treatment procedure, in this case the information and support received from the hospital staff;
- ideas about the future (prognosis);
- psychological stress experienced during the past year;
- (need for) contact with other partners or therapeutic aid;
- changes in life-attitudes;
- support given to the patient.

Sexuality and relationship
- quality of the relationship in general during the past year;
- quality of the sexual relationship before the treatment and during the past year;
- improvement in the relationship due to the experiences during the past year;
- the presence of sexual problems due to illness or treatment;
- the occurence of sexual rehabilitation.

6.6.3 Results

6.6.3.1 Involvement and support

Although the medical and nursing staff had endeavoured to provide optimal oral and written information for the patient and relatives, as can be seen in table I, the partners in general did not feel well-informed. Only three of them read the leaflet from the hospital thoroughly or approached the medical staff with questions. Three other men said they felt excluded from what happened to their wives at the hospital. They would have appreciated some more attention from the nurses and medical staff. This, however, does not mean that they have serious complaints about the way they

Table I Involvement and support (n=16)

	YES	NEUTRAL	NO	UNKNOWN
- Did you receive adequate information from the hospital?	3	2	8	3
- Did you receive adequate support from the hospital?	6	6	3	1
- Are you optimistic about the future?	9	5	2	-
- Did you experience psychological stress?	12	4	-	-
- Did you need professional help or support from fellow-sufferers?	2	1	10	3
- Did the event change your life-attitudes?	7	5	3	1
- Could you provide adequate support for your partner?	4	3	1	8

were supported by the hospital staff. Although 10 men were not satified with the information provided, only 3 men evaluated this support as really insufficient. It was not clear wether these men had read the written information.

Although the discovery of cancer was a shock to all the men, only 2 of them indicated that they feared a recidive. Nine men considered that the cancer had been treated satisfactorily and were optimistic about the future. The cancer had changed the life attitudes of 7 participants, making them more aware of non-materialistic values. However, factual changes in life-style were seldom reported.

For 12 men, their wife's cancer, the treatment and the following recovery period had led to a lot of stress, although only 6 of them had reported severe stress. The other half had found the stress tolerable. Most stressful were the shock of the diagnosis, the disturbed daily life and the process of providing emotional support for their wives.

Four men sincerely doubted whether they had adequately supported their wife. Most men welcomed the idea of professional psycho-social aid for their wife, especially when they had sexual problems, but for themselves, however, professional aid or contact with fellow-sufferers (other partners) had hardly been considered. Only 2 men, both having severe problems with their relationship due to the disease and its treatment, indicated the need for professional help for themselves during the past year.

6.6.3.2 Sexuality and relationship

Table II shows that at the time of the interview, the participants had a reasonably good relationship with the patients; 7 men had a good or even very good relationship and indicated that their relationship had strengthened during the past year. For the

Table II Sexuality and relationship (n=16).

	POS	NEUTRAL	NEG	UNKNOWN
- What is the quality of your relationship in general?	7	6	3	-
- What was the quality of your sexual relationship before treatment?	9	3	4	-
- What is the quality of your sexual relationship at this moment?	4	2	10	-
	YES	NEUTRAL	NO	UNKNOWN
- Has your relationship strengthened during the past year?	7	9	-	-
- Do you have sexual problems?	6	6	4	-
- Are you undergoing sexual rehabilitation?	6	3	3	4

other men, the quality of the relationship had remained the same or worsened during this period. Two men who already had a poor relationship beforehand, demonstrated inordinately negative feelings towards their wife at the time of the interview. Only 4 men had a rewarding sex life with their wife at the time of the interview. For the other 12 men, sex with their wife was problematical, with varying degrees of seriousness. Seven men already had an unsatisfying sexual relationship before the discovery of cancer, which became even worse because of the treatment. In the eyes of 5 men, the problems originated directly from the cancer treatment.

6.6.4 Discussion

Some methodological problems limit the validity and generalizability of our results. Firstly, the participants gave retrospective opinions about the period before and during the treatment of their wife. It is likely that these opinions were coloured by their recent experiences. Secondly our participants comprised a small and probably selected group, because the patients who participated in the overall study were not a random population and of all the partners who were invited to participate, only 16 actually did, while 8 refused. The results of this study can therefore best be seen as a first guide-line for further research.

With regard to involvement and support, it appeared that although many men experienced the process of providing emotional support for their partner as a stressful process and some men indicated having serious doubts about their qualities as a provider of emotional support, only 2 of them were interested in professional aid. In accordance with Leiber's results[8], an explanation for this phenomenon could be that these men became more rigid and stereotypical in their male role due to the crisis of cancer. Owing to the fact that a "real" man solves his problems alone, coping with his wife's disease becomes a solitary event.

With regard to sexuality and relationship, the results of this study make it clear that these partners certainly do have extensive sexual problems, which they mainly attribute to the lack of sexual motivation and satisfaction of their wife. Although no direct questions were asked, regarding a reason for their sexual problems, some men mentioned that sex had became less satisfying because their wife did not enjoy sex anymore. Due to physical and/or emotional problems, sex had become "a mechanical event instead of a game for two", as one man put it. Vennix[10] recently found that in a non-patient population, many men experience their partners orgasm as more important than their own. Therefore, it is not suprising that for the participants in this study, anorgasmy and the lack of sexual enthusiasm from their partner, made sex a frustrating experience, which led to feelings of incompetence and guilt.

It was striking that the partners never mentioned a possible solution for these rather extensive problems in the form of talking about the meaning of sexuality and about the changes caused by the process of cancer treatment. When minor problems arose, the men simply waited until their wife was willing to have sex again. Searching for more satisfying alternative forms of sexual interaction with the patient was seldom reported by the men. After such a dramatic life-event, one could have expected more openness towards alternative solutions. As the main reasons for this "lack of creativity", some men mentioned that they did not think that their wives

could have handled experiments with sex in this period and that in any case their wives were more conservative in their sexual behaviour, even before treatment, i.e. they showed a lack of inclination towards manual or oral-genital stimulation. Forms of non-genital intimate interaction were appreciated and regarded as being of importance, especially for the wives, but were not experienced by the participants as "real" sexual contact.

In the light of the findings in the field of coping with disease, it can therefore be hypothesized that a rather rigid masculin behaviour pattern will emerge with regard to sexuality. Unfortunately, the male sex role leaves little room for non-genital sexual behaviour or for the discussion of one's own sexual feelings and motives. This makes problem solving in this area, under these circumstances, nearly impossible. To be able to solve sexual problems and to restore feelings of mutuality and intimacy, there must be adequate communication between the partners about these matters. Adequate communication on sexual matters was seldom reported by our participants.

A possible explanation for this omission might be found in the fact that one of the most important preconditions for communication itself is not fulfilled. This precondition is that each individual partner must have the capacity to decenter his/herself and adopt the perspective of the other partner.[11] As (gynaecological) cancer not only poses a crisis for the patient but also for her partner, it can be hypothesized that these partners are not able to fulfil this condition because of their own emotional disturbance.

Instead of a flexible changing of perspectives, the male partners show regression towards a more rigid way of coping, which is strongly connected with the sex role, thereby making communication about sexuality very difficult, if not impossible during that period.

The most striking advantage of rigid sex roles is probably their ability to reduce uncertainty in social situations. Therefore rigid sex roles can be expected to persist more frequently and intensively during periods of crisis. The price that one has to pay for this advantage, however, is not only a strong reduction in the freedom and variety of behaviour, but probably also a loss of joint problem solving, mutuality and intimacy.

According to Wynne[12] the processes of attachment/careprovision, communication, joint problem solving, mutuality and intimacy, are to be seen as sequential phases in the development (epigenesis) of long-term relationships. Problems during one of these phases, or attemps to bypass one of these phases, are apt to generate impasses and dysfunctions or constrict subsequent growth.

Practically speaking, this means that joint problem solving is only possible if the underlying process of communication is functioning well. Intimacy, as the final stage and the most highly valued type of relatedness, is only within reach when the whole hierarchy of underlying processes is functioning adequately. From this point of view, the restricting effect that the crisis of cancer has on an individual's interpersonal behaviour, is probably best seen as a "chain reaction". This means that, in order to prevent sexual and relationship problems after treatment, attention should not only be given to the patient during treatment, but also to her partner and to their communication patterns.

REFERENCES

1. GLOECKNER, M.R. (1983) Partner reaction following ostomy surgery. Journal of Sex and Marital Therapy, vol.9, pp. 396-405.
2. WELLISCH, D.K., JAMISON, K.R. & PASNAU, R.O. (1978) Psychological aspects of mastectomy: II. The men's perspective. American Journal of Psychiatry, 135, pp. 543-546.
3. LICHTMAN, R.R. & TAYLOR, S.E. (1986) Close relationships and the female cancer patient. In: B.L. Andersen (Ed.) Women with cancer: Psychological perspectives, Springer, New York, pp. 233-256.
4. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecological Oncology, 4, pp. 275-281.
5. ADELMAN, J.M. (1984) Husbands' responses to their wives' gynecologic cancer. Los Angeles, Dissertation.
6. COOK GOTAY, C. (1984) The experience of cancer during early and advanced stages: the view of patients and their mates. Social Science Medicine, 18: pp. 605-613.
7. WORTMAN, C.B. & DUNKEL-SCHETTER, C. (1979) Interpersonal relationships and cancer: A theoretical analysis. Journal of Social Issues, 35, pp. 120-155.
8. LEIBER, L, PLUMB, M.M., GERSTENZANG, M.L. & HOLLAND, J. (1976) The communication of affection between cancer patients and their spouses. Psychosomatic Medicine, 38, pp. 379-389.
9. MORRIS, T, GREER, H.S. & WHITE, P. (1977) Psychological and social adjustment to mastectomy: a two-year follow-up study. Cancer, 40, pp. 2381-2387.
10. VENNIX, P. (1989) Seks en sekse. Delft, Eburon.
11. BLAKAR, R.M. (1984) Communication: a social perspective on clinical issues. Oslo, Universitetsforlaget.
12. WYNNE, L.C. (1984) The epigenesis of relational systems: A model for understanding family development. Family Process, 23, pp. 297-318.

6.7 Psychosexual functioning after treatment for cancer of the cervix, a comparative and longitudinal study*

Summary

Twenty-six couples participated in a 2-year longitudinal study on sexual functioning before and after treatment for carcinoma of the cervix. Sexual functioning was measured on admission prior to their treatment and at 6, 12 and 24 months follow-up and made operational in terms of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, and the perception of genital sensations of sexual arousal. An age-matched nonpatient control group was added to the study. In addition, the results of a 1 year longitudinal assessment of sexual functioning of women diagnosed and treated by means of simple hysterectomy for benign gynaecological disease were used for comparison. The impact of physical variables and participation in the research project was also evaluated.

* W.C.M. Weijmar Schultz, H.B.M. van de Wiel & J. Bouma (1991) Accepted by the International Journal of Gynaecologic Oncology.

At 1-year follow-up sexual functioning of the women who had been treated for carcinoma of the cervix was very similar to sexual functioning of the women who underwent simple hysterectomy for benign disease: in both populations the sexual response was significantly disturbed, whereas current sexual behaviour and motivation for sexual interaction were within the normal range. The women clearly expressed general satisfaction with their sexual functioning and little relational sexual dissatisfaction.

These data demonstrate that a woman's motivation for and satisfaction with sexual interaction with the partner is not limited to the experience of sexual arousal and that sexual rehabilitation aimed specifically at the diagnosis of cancer and the associated physical variables is not really justified.

6.7.1 Introduction

Sexual-functioning-morbidity estimates in retrospective studies of patients treated for cervical cancer range from 6 to 100% of the patients surveyed.[1] In the light of the results of pre-post treatment studies a less dramatic and more differentiated picture with regard to sexual-functioning-morbidity can be drawn . These latter studies show deterioration of sexual functioning, but only in as far as it concerns the symptomatic period preceding the discovery of gynaecological malignant disease and the period right after diagnosis and treatment.[2-9] Beyond this period, the deterioration in sexual functioning is less extreme than in the post-treatment studies, range from 0-40%. This may be due to the different approach to women's sexual functioning by using more specific methods of operationalization and analysis in the pre-post-treatment studies. Moreover, participation in a pre-post-treatment study may have indirectly encouraged the patients to discuss sexual matters and/or to remain sexually active after the treatment.

Studies, using more specific methods of operationalization, support the picture that despite major physical losses and substantial emotional disruption, women attempt to maintain a sexual life. These studies, however, hardly indicate which factors related to the disease and its treatment do elicit and control sexual behaviour after treatment for gynaecological cancer.

In an effort to provide insight into the complicated issue of sexual functioning after gynaecological cancer treatment, the sexual functioning of women with cervical cancer was compared 1) with the sexual functioning of an age-matched group of gynaecologically healthy women, 2) with an age-matched control group of women who underwent simple hysterectomy for benign disease, before treatment and one year afterwards, and 3) with an age-matched control group of women with cervical cancer whose sexual functioning was assessed only once, one year after their treatment.

Sexual functioning was made operational in terms of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, and the perception of genital sensations of sexual arousal. Also, physical variables (the perception of physical conditional hindrance, negative sensations during sexual arousal, dyspareunia and vaginal sensitivity) were measured. The impact of these physical variabels is discussed.

6.7.2 Methods

Women with cervical cancer, together with their partners, were invited to participate in the research project, when hospitalized but before treatment. Inclusion criteria included the following: (1) participants were younger than 70 years; and (2) absence of pre-treatment psychiatric or somatic disorders in one or both partners that might interfere with their sexual relationship.

The voluntary nature of participation was stressed and it was made explicitly clear that it would be possible to withdraw from the research programme at any time. Therefore no pressure was set on those who immediately refused to participate nor on those who ended their participation during the 24 months of the study. This procedure made analysis of refusers and drop-outs impossible.

6.7.2.1 Design

Assessments took place on admission, before treatment, and at 6, 12, and 24 months post-treatment. The 6-month period was chosen because it was considered long enough for the couples to have resumed "every day life" and for the social and other relevant problems resulting from the treatment to have manifested themselves.[2] The 12-month period was chosen because no more psychosexual changes induced by the disease or its treatment were expected after this period.[1] To verify this contention, and to study the long-term evolvement of sexual functioning in the cervical cancer patient group, a 24 month assessment was added to the study. A single assessment of a control group of age-matched gynaecologically healthy women was made using the standardized measures of sexual functioning for comparison (1st control group).

In addition, the results of a one year longitudinal assessment of women diagnosed and treated by simple hysterectomy for benign gynaecological disease (2nd control group) were used for comparison. A 3rd control group of women treated for cervical cancer whose sexual functioning was only assessed once one year after the treatment was added to the design to test whether participation in a prospective study influenced the post-treatment evaluation of sexual functioning, the socalled "testing" effect. The results were analysed statistically by means of Student *t*-tests and Manova repeated measurements procedures.[10]

In this study, sexual functioning is defined as a rather broad construct that covers the following aspects of sexuality: current sexual behaviour (overt manifestations of sexual behaviour); libido or sexual motivation (the wish for and appreciation of sexual interaction); sexual (dis)satisfaction (the emotional outcome of sexual interaction in terms of a global overall judgement); and the perception of genital symptoms of sexual arousal and orgasm (the sexual response).

To measure current sexual behaviour, sexual motivation and sexual(dis)satisfaction, the Intimate Bodily Contact Scale (IBCS) of Vennix was used.[11] The IBCS is an extensive self-report questionnaire which contains 22 subscales, covering various aspects of sexual functioning. The scales are standardized for heterosexual Dutch men and women separately and the internal consistency is generally high. The IBCS is based on Rotter's theory on social learning and assesses people's expectancies about the outcomes of sexual interaction. Scores on the IBCS are therefore expressed in terms of "expectancy percentages"; e.g. a score of 80.0 on IBCS-1 (frequency of

intimacy) means that the patient's expectation that feelings of intimacy will be experienced during lovemaking is 80 percent. The score range of the subscales of the IBCS, except the general satisfaction with sexual interaction scale (GSS), runs from 0 to 100. The GSS score range runs from 5 to 34 and is no expectancy percentage. In order to avoid overburdening the patients, only a limited number of subscales of the complete IBCS were used.

To measure sexual arousability and the perception of genital symptoms of sexual arousal during lovemaking an arousability scale (GAS) was developed. The GAS is a self-report questionnaire based upon the work of Masters and Johnson[12], Kaplan[13] and Hoon et al.[14] and contains four subscales: (1) perception of positive genital sensations during sexual arousal, GSSUM (eight items; $\alpha = .83$); (2) perception of positive genital sensations during orgasm, OSSUM (four items; $\alpha = .78$); (3) perception of negative genital sensations during sexual arousal and orgasm, NEGSUM (five items; $\alpha = .67$); and (4) the ability to induce sexual arousal and orgasm, CAPSUM (six items; $\alpha = .79$).

The "perception of physical conditional hindrance" (IBCS 13) and the occurrence of dyspareunia were also included in this study. The IBCS 13 (six items; $\alpha = .87$) measures general mood disturbances which may interfere with the motivation for and outcome of sexual interaction, e.g., feelings of tiredness and actual physical fatigue. The occurrence of dyspareunia was asked for in detail at each subsequent visit to the gynaecologist.

In cervical cancer patients of the longitudinal sample the vaginal sensitivity was measured. Vaginal sensivity was measured by means of an electric stimulus and expressed in terms of a Vaginal Sensitivity Threshold (VST), i.e., the smallest intensity of an electric current, expressed in milliamperes, which, at a certain frequency and duration of the stimulus, evokes a prickly sensation. This method of measuring sensitivity was specially designed for this study and further details of it have been published elsewhere.[15] The VST-control-group is not matched on age (n=58, mean age 29 years, range=18-60, mode 24.0, median 27.1).

Each assessment of the subject included an examination by the gynaecologist to check up on and exclude recurrence of the disease or the presence of any other diseases which might interfere with sexual functioning. Before the treatment, participants were informed about the investigation and asked to complete the questionnaires. Later on, questionnaires were sent to them by mail and returned during a subsequent visit to the gynaecologist. Control visits were quite exactly scheduled at a 6, 12 and 24 months rate after treatment. Instructions were given not to communicate on the completion of the questionnaires in order to prevent underreporting of psychosexual problems.

6.7.2.2 Subjects

The cervical cancer patient population Seventy-two women and their partners were invited to participate in the research project. None of these women or their partners had a history of psychiatric or somatic disorders which might have interfered with their sexual relationship. Eighteen couples did not wish to participate, mainly for emotional reasons: they found participation too distressing in the light of the

cancer diagnosis and treatment. Fifty-four couples participated in the project. This means a response of 75%. All the women were scheduled to undergo treatment for cancer of the cervix. During the period of investigation, 28 participants were lost to follow-up (5 couples because they moved, 9 couples because of cancer recurrence, 6 couples because of deteriorated physical condition and 8 couples because of study drop-out) leaving 26 couples for evaluation. There was no significant difference in age, marital status and education between the non-response group, the drop-out group and the women who participated in the study. The women had the following stages of cervical cancer: stage Ib (n=15), stage IIa (n=5), stage IIb (n=5) and stage IIIb (n=1). All the women received treatment consisting of surgery (radical hysterectomy, n=12), or radiotherapy (n=1) or combination therapy (radical hysterectomy preceded by radiotherapy, n=13). A demographic analysis revealed that the mean age was 39 years (range=18-64), that 70% of the sample were premenopausal and that all of the participants, except for one, were involved in a stable heterosexual relationship at the time of the study.

On admission, most of the women had physical complaints which possibly interfered with the sexual relationship, including some abnormal bleeding in 58% of the women in the form of postcoital bleeding (n=10), abnormal menstrual bleeding (n=1), intermenstrual (n=6) or postmenopausal bleeding (n=8). Other complaints were vaginal discharge (n=13) and dyspareunia (n=5).

Partners of the women involved in this study were interviewed 12 months post-treatment. The results of these interviews have been reported in another article.[16]

The control/simple hysterectomy population For this group, the same exclusion criteria were used as for the cervical cancer patient population. Ten women participated in the simple hystectomy group: mean age 43 years (range 30 to 65 years).

The control/healthy population The healthy control group comprised 21 women: mean age 42 years (range 20-58 years). Most of the younger women in this group were patients visiting the clinic on a regular basis for contraception and most of the older women were recruited via an advertisement.

The "testing" control group This group consisted of 12 women who were treated for cervical cancer. In this group of women a single assessment was made at 12 months follow up. Since the sample size of the control/simple hysterectomy population and the "testing" control group is very modest these control groups have to be considered as "indicative".

6.7.3 Results

The development, over time, of current sexual behaviour, sexual motivation, sexual (dis)satisfaction, perception of genital symptoms during sexual arousal and additional somatic variables is presented in Tables 1 to 6. Tables 1, 2 and 3 include the mean values of women treated for cervical cancer and the mean values with standard deviations of the age-matched control group of gynaecologically healthy women.

Tables 4, 5 and 6 include the mean values of women diagnosed as having benign gynaecological disease who were treated by means of simple hysterectomy and, again, the mean values with standard deviations of the age-matched control group of gynaecologically healthy women.

Table I Group means on current sexual behaviour and motivation for sexual interaction of women diagnosed and treated for cervical cancer before treatment and at 6-month, 1-year and 2-year follow-up (n=26) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	2-Yr	control group healthy women (+SD)
Current sexual behavior					
Frequency of intimacy (IBCS1)*	82.7	84.4	80.4	82.4	79.1 (12.6)
Frequency of intimacy-inducing-behaviour (IBCS19)*	68.9	68.5	73.9	73.1	66.1 (7.9)
Frequency of arousal (IBCS2)*	73.3	70.4	67.4	67.9	70.4 (14.7)
Frequency of arousal-inducing-behaviour (IBCS20)*	62.1	62.1	62.0	59.6	63.6 (13.0)
Sexual motivation (libido)					
Appreciation of intimacy (IBCS7)*	87.8	79.4	82.3	86.7	87.7 (18.7)
Appreciation of intimacy-inducing-behaviour (IBCS8)*	81.0	69.2	71.5	71.2	81.8 (10.0)
Appreciation of arousal (IBCS21)*	85.7	83.1	86.1	86.9	84.4 (6.3)
Appreciation of arousal-inducing-behaviour (IBCS22)*	70.6	65.7	62.6	62.9	68.3 (14.8)

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).

Before treatment, the cervical cancer patient group differed from the control group of gynaecologically healthy women only with regard to the capacity to induce sexual arousal and orgasm and relational sexual dissatisfaction. In the former group, the capacity to induce sexual arousal and orgasm was low ($p < .001$), while relational sexual dissatisfaction was very low in comparison with the control group ($p < .001$).

One year after cervical cancer treatment, there was no difference between the cervical cancer patients and the gynaecologically healthy control group regarding current sexual behaviour and motivation for sexual interaction. The sexual response, however, appeared to have deteriorated on all subvariables in the cancer treatment group ($p \leq .05$). Also, in comparison with the gynaecologically healthy control group, negative genital sensations during sexual arousal and orgasm were more frequently reported ($p < .05$). Only one woman mentioned dyspareunia as a problem. General sexual satisfaction remained undisturbed. In comparison with the pre-treatment situation, relational sexual dissatisfaction increased but was still less than in the gynaecologically healthy control group ($p \leq .05$). One year after the treatment, the vaginal sensitivity threshold was high. The difference in VST between the cancer treatment patients and the control group of gynaecologically healthy women was significant ($p < .01$).

Table II Group means on the perception of genital symptoms of sexual arousal and sexual (dis) satisfaction of women treated for cervical cancer before treatment and at 6-month, 1 year and 2-year follow-up (n=26) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	2-Yr	control group healthy women (+SD)
Genital symptoms of sexual arousal					
Positive genital sensations during arousal (GSSUM)*	55.6	36.7	43.7	51.8	60.8 (17.8)
Positive genital sensations during orgasm (OSSUM)*	70.9	64.6	65.1	59.9	76.3 (15.8)
Ability to induce sexual arousal and orgasm (CAPSUM)*	46.9	41.5	44.7	40.0	62.6 (14.8)
Sexual (dis)satisfaction					
General satisfaction with sexual interaction (GSS)**	30.2	30.2	28.5	28.7	28.7 (3.1)
Relational sexual dissatisfaction (IBCS5)*	9.3	17.1	14.4	15.0	24.2 (23.3)

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).
** Mean score (range 5-34).

Table III Group means on additional somatic variables of women diagnosed and treated for cervical cancer before treatment and at 6-month, 1-year and 2-year follow-up (n=26) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	2-Yr	control group healthy women (+SD)
Additional somatic variables					
Vaginal sensitivity threshold (VST)***	3.3	4.7	4.4	3.9	2.6 (1.4)
Negative genital sensations during sexual arousal and orgasm (NEGSUM)*	10.5	22.0	22.7	33.3	12.8 (6.9)
Perception of physical conditional hindrance (IBCS13)*	38.0	38.6	32.0	39.6	32.2 (14.1)
Dyspareunia*	19.0	8.0	4.0		

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).
*** Mean score (in mA).

Table IV Group means on current sexual behaviour and motivation for sexual interaction of women diagnosed and treated with simple hysterectomy for benign gynaecological disease before treatment and at 6-month and 12-months follow-up (n=10) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	control group healthy women (+SD)
Current sexual behaviour				
Frequency of intimacy (IBCS1)*	67.6	80.6	80.0	79.1 (12.6)
Frequency of intimacy-inducing-behaviour (IBCS19)*	49.0	58.8	56.6	66.1 (7.9)
Frequency of arousal (IBCS2)*	60.4	67.0	69.2	70.4 (14.7)
Frequency of arousal-inducing-behaviour (IBCS20)*	45.1	54.9	55.9	63.6 (13.0)
Sexual motivation (libido)				
Appreciation of intimacy (IBCS7)*	71.8	76.5	86.7	87.7 (18.7)
Appreciation of intimacy-inducing-behaviour (IBCS8)*	68.9	76.4	81.9	81.8 (10.0)
Appreciation of arousal (IBCS21)*	70.2	77.5	77.2	84.4 (6.3)
Appreciation of arousal-inducing-behaviour (IBCS22)*	56.9	62.0	58.8	68.3 (14.8)

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).

In the second year after the treatment, an increase was observed in the cancer treatment group with regard to negative genital sensations during sexual arousal and orgasm and physical conditional hindrance; the VST partly recovered, while the remaining variables hardly changed.

Multivariate repeated measurement analysis of variance in the cervical cancer patient group revealed a significant time effect on the appreciation of arousal-inducing behaviour ($p < .039$), on the vaginal sensitivity threshold ($p < .001$) and on physical conditional hindrance ($p < .003$).

One year after the treatment no significant differences could be found between the sexual functioning of the multiple assessed cervical cancer patient group and the control group of cervical cancer patients whose sexual functioning was assessed only once.

The sexual functioning of women prior to simple hysterectomy for benign gynaecological disease appeared to be seriously disrupted. In comparison with the gynaecologically healthy control group, motivation for sexual interaction and current sexual behaviour was very low ($p < .05$). Also the sexual response was low on all subvariables ($p < .001$). General sexual satisfaction, relational sexual dissatisfaction and physical conditional hindrance were within the normal range. Negative sensations during sexual arousal and orgasm were observed less frequently than in

Table V Group means on the perception of genital symptoms of sexual arousal and sexual (dis)satisfaction of women diagnosed and treated with simple hysterectomy for gynaecological benign disease before treatment and at 6-month and 12-month follow-up (n=10) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	control group healthy women (+SD)
Genital symptoms of sexual arousal				
Positive genital sensations during arousal (GSSUM)*	37.7	40.4	45.6	60.8 (17.8)
Positive genital sensations during orgasm (OSSUM)*	54.6	55.2	52.4	76.3 (15.8)
Ability to induce sexual arousal and orgasm (CAPSUM)*	45.0	41.9	50.0	62.6 (14.8)
Sexual (dis)satisfaction				
General satisfaction with sexual interaction (GSS)**	28.0	28.6	28.3	28.7 (3.1)
Relational sexual dissatisfaction (IBCS5)*	16.0	10.4	9.5	24.2 (23.3)

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).
** Mean score (range 5-34).

Table VI Group means on additional somatic variables of women diagnosed and treated with simple hysterectomy for gynaecological benign disease before treatment and at 6-month and 12-month follow-up (n=10) and of women in a control group of gynaecologically healthy women (n=21)

	Initial	6-Mo	1-Yr	control group healthy women (+SD)
Additional somatic variables				
Negative genital sensations during sexual arousal and orgasm (NEGSUM)*	7.4	18.2	24.1	12.8 (6.9)
Perception of physical conditional hindrance (IBCS13)*	30.5	59.0	54.2	32.2 (14.1)

IBCS: intimate bodily contact scale.
* Mean score (range 0%-100%).

the healthy control population ($p < .05$). The vaginal sensitivity threshold was not measured in this patient population.

After the simple hysterectomy, current sexual behaviour and motivation for sexual interaction re-established themselves to within the normal range, whereas the sexual response remained disturbed on all its subvariables ($p < .05$). Negative sensations

during sexual arousal and orgasm increased but, in comparison with the control population, re-established themselves to within the normal range. The physical conditional hindrance continued to be high ($p < .001$). The general sexual satisfaction remained undisturbed. Relational sexual dissatisfaction was observed less frequently than in the control population of gynaecologically healthy women ($p \leq .01$).

Multivariate repeated measurement analyses of variance of the simple hysterectomy patient group revealed no significant time effect.

6.7.4 Discussion

In this longitudinal study on psychosexual functioning after treatment for cancer of the cervix, the primary assessment was conducted during admission but before treatment. Although this is an exceedingly difficult time for patients and their partners, 54 out of 76 couples agreed to participate in the study. The final sample comprised 26 women and their partners.

On admission, all of the women with cervical cancer had physical complaints. These symptoms may have already affected sexual functioning[17,18] However, there was hardly any difference between the sexual functioning of the cervical cancer patient group and an age-matched gynaecologically healthy control group, despite the patient group's multiple physical complaints. In the control group of women with gynaecologically benign disease, however, sexual functioning was seriously disturbed prior to their simple hysterectomy. The long-term period of conservative treatment for benign gynaecological disease may have intensified the impact of symptoms on sexual functioning in this group of women, in contrast to confrontation with malignant gynaecological disease which calls for immediate action.

Remarkably enough, at 1-year follow-up sexual functioning of the women who underwent simple hysterectomy for benign disease was very similar to sexual functioning of the women one year after cervical cancer treatment: in both populations the sexual response was significantly disturbed, whereas current sexual behaviour and motivation for sexual interaction were within the normal range. Concomitantly, more negative genital sensations during sexual arousal and orgasm were reported in the patient groups. These negative sensations consisted in particular of having the feeling that the vagina was too narrow, too short or was feeling numb. In contrast to these increasing negative sensations during sexual arousal and orgasm, the frequency of dyspareunia, studied separately in the cervical cancer patient group, was remarkably low. Besides, the women clearly expressed general satisfaction with their sexual functioning and little relational sexual dissatisfaction.

These data demonstrate that a woman's motivation for and satisfaction with sexual interaction with the partner is not limited to the experience of sexual arousal. A whole range of motives may be involved. Within our Western culture, in essence two basic motives for sexual behaviour can be distinguished: attempts are being made to fulfil the need for "intimacy" and attempts are being made to fulfil the need for "arousal".[19-21] For women, intimacy comes first. If, in times of crisis, sexual functioning contributes her longing for intimacy, she will easily assess her sexual interaction with her partner as satisfactory, despite of a persisting poor perception of genital symptoms of sexual arousal due to insufficient arousal. Women who have recently been treated for cervical cancer are inclined to adapt to their partner rather

than vice versa: "Not feeling any personal need for sexual interaction" is incompatible with what Weeda[22] calls the female "love ethos", i.e. the solemn duty a woman feels to take care of her partner, including his sexual needs. Moreover, these women, due to their condition, feel excessively dependent on their partner. This could also explain the remarkably low level of relational sexual dissatisfaction throughout the observation period. Also negative motives may be involved, such as the fear of losing one's partner.

Dyspareunia has frequently been considered to be a significant disruptor. However, in our experimental patient population, the persisting poor sexual response was not dyspareunia-based: the frequency of dyspareunia was low and declined with time. We were given the impression that, because of the disease and its treatment, the women were feeling alienated from their genital area. In fact, women reported changed feelings in the genital area during intercourse: in the cervical cancer patient group, the reported feeling of vaginal numbness matched the measured increase in the vaginal sensitivity threshold. Physical examination showed vaginal shortening in nearly seventy percent of the cervical cancer patient group, with a remarkable absence of vaginal stenosis.

Fatigue is a well-known consequence of cancer treatment. This was clearly reflected in the increased levels of physical conditional hindrance. Also on this issue, the group of women with simple hysterectomy was similar to the group of women with cervical cancer. This means that fatigue is more an effect of gynaecological treatment than of the diagnosis and treatment of cancer per se. Fatigue by itself can damage or eradicate sexual functioning.

Ionizing radiation has a direct effect on the basal layer of the vaginal epithelium, which is highly radiosensitive, on the endothelium of the small vessels and on the fibroblasts of the connective tissue in the subepithelium which are moderately sensitive.[23] Narrowing and obliteration of the small vessels and the increase in fibrosis, restricts the vascular system's ability to dilate, thus inhibiting vasocongestion/lubrication and the sensory nerve responses integral to arousal and the achievement of orgasm. Schover et al.[7] reported on the delayed impact of radiotherapy on women's sexual functioning. In her study, she divided her study population into women treated with surgery alone, surgery with radiation and radiotherapy alone. The radiotherapy group, whether or not in conbination with surgery, developed dyspareunia and had more problems with sexual desire and arousal than the surgery-alone group. Vincent et al.,[2] after assigning cancer patients at random to surgical treatment or radiotherapy, but using less specific methods of operationalization, did not find a difference in sexual functioning of women treated with surgery alone and radiotherapy alone. Post hoc analysis of our data on this issue, without random assignment to the various treatment modes, did reveal a significant difference between the surgery-alone group and the group of women who received surgery and radiotherapy. One year post-treatment the women who had undergone combination therapy reported significantly fewer genital symptoms of sexual arousal on all the subvariables ($p < .05$). Two years post-treatment, the differences between these treatment modalities had disappeared, except for genital sensations during orgasm. Similar to the observations made by Hansen[3], in the combined treatment group no

radiation-induced changes were observed, i.e. no vaginal stenosis and fibrosis. This may be due to the much lower total dose of radiation they received compared to the patients who were treated with radiation alone. Moreover, in the former patients, the upper 1/3 of the vagina, which is normally exposed to the largest dose of radiation, had been removed during the operation. This might explain the absence of dyspareunia in our patient population in contrast to Schover.[7] Many of the women in her experimental patient population were treated with radiotherapy alone.

We have found evidence for a change in neural innervation after radical hysterectomy, expressed as a temporary increase in the vaginal sensitivity threshold. Autonomic and sensory nerves are closely intertwined, therefore disruption of the sensory nerves automatically disrupts the autonomic nerve supply to the vagina and surrounding vessels. Damage to these nerves will be detrimental to vaginal vasocongestion, lubrication, expansion and sensory perception during arousal and coitus.

Studies on the neurophysiologic function of the genito-urinary tract after radical hysterectomy, dealing with bladder function, suggest that the degree of urinary dysfunction is dependent on the radicality of the operation, with special emphasis on the length of the vaginal cuff removed and on the extent of lateral dissection.[1] Post hoc analysis of our data on the effect of the length of the vaginal cuff removed and on the extent of lateral dissection did not reveal any significant difference.

In the cervical cancer patient group at the two-year follow-up assessment negative genital sensations during sexual arousal and orgasm were found to have increased as well as the perception of physical conditional hindrance. Therefore it must be concluded that the effect of cervical cancer on psychosexual functioning ranges over more than one year. The most obvious explanation is that this is the delayed impact of radiation therapy. Post hoc analysis, however, revealed no significant difference in negative genital sensations during sexual arousal and orgasm and physical conditional hindrance between the women treated with surgery alone (n=12) and the women treated with combination therapy (n=13).

These findings make it clear that gynaecological patients, whether treated for malignant or benign diseases, face stressful, even traumatic events and show deterioration in their psychosexual functioning even 1 and 2 years after treatment. However, despite a persisting poor sexual response and annoying physical complaints most of them attempt and manage to maintain a sexual life.The findings confirm the validity of former descriptions on this subject.[2,8] Because of the absence of differences between the experimental patient population and the "testing" control group it seems unlikely that participation in the pre-post research project has had a positive impact on these results.

The similarity in sexual functioning between the women with benign gynaecological disease and the women with cervical cancer diagnosis at one-year follow-up, shows that sexual rehabilitation aimed specifically at the diagnosis of cancer and the associated physical variables is not really justified. It looks as if it would be better to aim any rehabilitation programmes at dealing with confrontation with a stressful gynaecological event and with coping strategies, in particular communication and mutual problem solving. Psychophysiological studies on the sexuality of women treated for benign or malignant gynaecological disease might yield more knowledge

about deterioration of the sexual response. In the future psychophysiologic techniques might be important intervention tools in psychosexual counselling programmes. Moreover, contextual factors contributing to a less satisfying psychosexual functioning constitute a very important target for future research and intervention.

REFERENCES

1. WEIJMAR SCHULTZ, W.C.M., BRANSFIELD, D.D., WIEL, H.B.M. VAN DE & BOUMA, J. (1991) Sexual outcome following female genital cancer treatment, a critical review of methods of investigation and results. Sexual and Marital Therapy, in press.
2. VINCENT, C.E., VINCENT, B., GREISS, F.C., LINTON, E.B. (1975) Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
3. HANSEN, M.K. (1981) Surgical and combination therapy of cancer of the cervix uteri stages Ib and IIa. Gynecologic Oncology, 11, pp. 275-87.
4. POULSEN, H.K., KRISTENSEN, G.B. & HANSEN, M.K. (1983) Seksuel dysfuncktion efter operation for cancer cervicis uteri stadium IB og IIA. Ugeskrift for Laeger, 145, pp. 162-164.
5. ANDERSEN, B.L., LACHENBRUCH, P.A., ANDERSON, B. & DEPROSSE, C. (1986) Sexual dysfunction and signs of gynecologic cancer. Cancer, 55, pp. 1880-1886.
6. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecologic Oncology, 9, pp. 275-281.
7. SCHOVER, L.R., FIFE, M. & GERSHENSON, D.M. (1989) Sexual dysfunction and treatment for early stage cervical cancer. Cancer, 63, pp. 204-212.
8. ANDERSEN, B.L., ANDERSON, B. & DEPROSSE, C. (1989) Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. Journal of Consulting and Clinical Psychology, 57, pp. 683-691.
9. ANDERSEN, B.L., ANDERSON, B. & DEPROSSE, C. (1989) Controlled prospective longitudinal study of women with cancer: II. Psychological outcomes. Journal of Consulting and Clinical Psychology, 57, pp. 692-697.
10. NORUSIS, M.J. (1988) SPSS/PC+ Advanced Statistics. Chicago, SPSS Inc.
11. VENNIX, P. (1983) De ILKS gedachte. Zeist, NISSO.
12. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
13. KAPLAN, H.S. (1979) Disorders of Sexual Desire. New York, Brunner/Mazel.
14. HOON, E.F., HOON P.W. & WINCZE J.P. (1976) An inventory for the measurement of female sexual arousability: the SAI Archives of Sexual Behavior, 5, pp. 291-300.
15. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, KLATTER, J.A., STURM, B.E. & NAUTA, J. (1988) Genital Sensivity for electric stimuli, theoretical and practical implications. Archives of Sexual Behaviour, 18, pp. 87-95.
16. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., WOUDA, J. & BOUMA, J. (1990) Sexual functioning of partners of gynaecological oncology patients; a pilot study on involvement, support, sexuality and relationship. Sexual and Marital Therapy, 5, pp. 123-130.

17. ANDERSEN, B.L. (1986) Sexual difficulties for women following cancer treatment. In: Andersen, B.L. (Ed.) Women with cancer, psychological perspectives. New York, Springer Verlag, pp. 257-288.
18. MANTELL, J.E. (1983) The psychosocial and physiological effects of invasive gynecologic cancers on female sexuality. In: Dennerstein, L., De Senarclens, M., (Eds.) The young woman: psychosomatic aspects of Obstetrics and Gynecology, Amsterdam: Exerpta Medica, pp. 398-408.
19. HITE. S. (1976) The Hite Report. New York, Macmillan.
20. JAYNE, C. (1981) Journal of Sex and Marital Therapy, 1: p. 7.
21. VENNIX, P. (1989) Seks en sekse. Groningen, Dissertation.
22. WEEDA, I. (1986) Over liefde gesproken. Houten, De Haan.
23. RUBIN, P., CASARETT, G.W. (1968) Clinical radiation pathology. Philadelphia, Saunders W.B.

6.8 Sexual functioning following treatment of cervical cancer*

Summary

Women faced with cervical carcinoma usually feel an increased need for support and attention, in particular from their partners as, at the same time an important part of the partner relation, sexual interaction often becomes problematic.

In this research the eventuality of a reduced sexual motivation in cervical cancer patients was investigated. It was found that sexual interaction is valued significantly less by women treated for cervical cancer than by women from a non-patient control group. After treatment no changes in overt sexual behaviour occur. Furthermore an effort was made to identify the most important psychosexual variables underlying the reduction in sexual motivation. It was found that a considerable decrease in the appraisal of oneself as a sexual partner is generally basic to the problem. Apparantly women try to cope by conforming to the sexual demands of their partners and with that of prevailing sexual norms.

It was concluded that cervical cancer treatment has a strong negative effect on the sexuality of the patients and that it often amplifies the already existing ambivalence towards sexual interaction in women.

6.8.1 Introduction

6.8.1.1 Incidence, treatment and prognosis

In The Netherlands every year over a 1000 women are faced with the diagnosis of cervical cancer. Cervical cancer can be treated by surgical therapy and/or radiotherapy. Operations usually consist of a "radical uterus extirpation" on which occasion the uterus, the tubes, the ovaries and the upper part of the vagina are removed. In addition lymph glands and a major part of the supporting tissue may be taken. When the operation is combined with radiotherapy, the latter can take place both before and/or after the operation.

* H.B.M. Van de Wiel, W.C.M. Weijmar Schultz, A. Hallensleben, F.G. Thurkow & J. Bouma (1988) European Journal of Gynaecologic Oncology, 4, pp. 275-281.

In particular cases surgery is avoided leaving just radiotherapy treatment. Especially when the illness is discovered in its early stages and there is no metastasis in the lymph glands, chances of survival are good, though the consequences are always far reaching in various respects. The combination of a good prognosis and radical treatment demands attention for possible longterm negative consequences.

6.8.1.2 Consequences of cervical cancer treatment for sexuality

Cancer is often looked upon as a breaking point in life because it leads to considerable changes in how people regard themselves and their future. Moreover, treatment frequently results in irreversible physical damage which in turn brings on changes in patterns of behaviour.[1] For instance, treatment of cervical cancer implies the loss of menstruation and fertility and in general a premature reaching of the menopause. In addition sexual functions are likely to be affected as a result of treatment. A change in bodily sensations during sexual arousal and pain during intercourse are frequently reported complaints.[2] Also a decrease in sexual arousability and orgasmic ability have been reported.[3] Consequently treatment of cervical carcinoma threatens an elementary aspect of human life.[4-5]

As Van Eschenbach and Schover[6] point out, sexuality for people suffering a life-threatening disease must be considered very important on the grounds of its function in maintaining intimate contact with others both physically and emotionally. In this context Hersch[7] denominates sexuality as the most ignored form of coping.

We consider it of importance that changes in the patient's sexual functioning are placed within the context of the partner-relationship.

Indirectly these changes may have severe consequences for the feeling of general well-being for both the patient and the partner. Sexual and other problems may upset the partner relation itself and therapy endanger an important source of social support. As Carenza et al.[8] found, many patients with cervical cancer continue to have regular sexual contact although feeling little sexual interest. This behaviour seems largely inspired by fear of losing the partner or by trying to prove to themselves that no fundamental change has occured.

The majority of papers discussing sexual problems arising as an effect of cervical cancer treatment consider physical obstruction and loss of sexual motivation and self-esteem the most important causes.[3,9] Empirical evidence for this however, is largely absent. Studies attempting to present such evidence are frequently heavily criticized on both their contents and methodology.[2,10,11]

The most heard criticism of the contents of such articles is that sexuality is almost exclusively defined in terms of overt sexual actions and that the emotional aspect, is left out of consideration. It is not uncommon that the frequency of coitus is the sole measure on which the quality of the sexual relation is judged. From this it appears that the experience of physical and emotional intimacy is not looked upon as an essential part in sexual functioning.

This is remarkable because from social-sexuological studies it appears that, in particular for women, the wish for such intimacy is considered the most important motive for engaging in sexual contacts.[12,13]

The validity of criticism on the methodological aspect is supported by the fact that in the various studies the percentage of women with sexual problems after treatment

of gynaecological cancer ranges from 0 to 80%.[10] Generally the use of prospective designs is being recommended[2,3,10] as the best method although such designs may give rise to methodological objections with respect to possible occurring "response shift bias".[14]

Designs in which relative changes with respect to control groups are considered are rare, as in the majority of studies the semi-structured interview is used as a method of data collection, which makes comparison hardly possible.

6.8.1.3 In summary

Women treated because of cervical cancer are facing a particular dilemma. The relationship with a lifecompanion becomes an important source of emotional support whereas a satisfactory sexual contact with the same person may be greatly hampered. Ambivalent feelings towards sexuality, which in women exist anyhow,[15] seem to be reinforced by the confrontation with cervical cancer which in turn may lead to additional problems in coping with the disease and treatment.

In order to realize good and effective ways to inform, guide and support patients, a thorough analysis of the changes which may occur as a result of this treatment is necessary.

Apart from overt behaviour, attention should also be paid to emotional and motivational aspects of the sexual behaviour because these, as feedback and as feed forward mechanism, greatly determine the eventual behaviour. Studies based on this consideration are thus far lacking.

In an attempt to fill up this gap a research project was started in 1983 in Groningen, financed by the Dutch Cancer Society. The focus of this project is sexual functioning after oncological gynaecological treatment. Cervical cancer is the most commonly occurring treatment in this respect. The present article concentrates on a group of 11 women who have undergone the treatment, and their partners. Changes in the "quality of sexual life" for these couples and the individuals forming them, before and after the treatment are evaluated.

6.8.1.4 Hypotheses

Treatment for cervical carcinoma has a negative impact on sexual functioning and more specifically:

1) There is a reduction in "satisfaction" with respect to sexual functioning.
2) Changes occur in the psychosexual situation which influences sexual functioning in a negative way.

6.8.2 Method

6.8.2.1 Population

Eleven women, age range 19-72, average age 46, treated for cervical cancer in the University Hospital participated. All women had undergone a radical hysterectomy and 6 women were additional treated with radiotherapy. All participants had a steady partner.

Ten women had a heterosexual relationship, one a lesbian relationship.

6.8.2.2 Procedure

During hospitalization, but before the actual treatment of carcinoma of the cervix patients and their partners were asked to participate in the project. The voluntary character of participation was stressed and it was made explicitly clear that the possibility to withdraw would remain open at all times.

Here results of the measurements taken 6 months after treatment are reported on. The 6 months period is regarded to be of sufficient duration to have social and other relevant problems resulting from, the treatment become manifest.[16]

6.8.2.3 Questionnaires

The Intimate Bodily Contact Scale (IBCS) of Vennix[17] was used in this research. The IBCS is a self-report questionnaire containing 22 subscales that together cover a large number of aspects of sexual functioning. Feelings and experiences, having intimate bodily contact, the value given to this, situational inhibiting factors, frequency of various aspects of sexual behaviour and appraisal given to this are just a sample.

The scales have separate norms for men and women and the internal consistency has proved to be generally high.

The evaluation of sexual functioning is operationalized in the three subsequent subscales of the IBCS:

- IBCS-6 (α = .91) measuring general sexual dissatisfaction
- IBCS-5 (α = .91) measuring relational sexual dissatisfaction
- ASS (α = .81) measuring general satisfaction with sexual interaction with the partners.

Changes in the psychosexual situations are operationalized in 4 subscales of the IBCS:

- IBCS-13 (α = .84), perception of mood disturbances.
- IBCS-15 (α = .73), perception of physical condition. This scale measures the amount of physical problems interfering with sexual functioning.
- IBCS-16 (α = .82), selfesteem as a sexual partner.
- IBCS-17 (α = .86), appreciation of the partner as a sexual partner.

The hypotheses are tested with the Student's *t*-test using a one sided significance level of .05.

Apart from the GSS, for all other scales used here the mean score corresponds with the expectation in percentages of the aspect occurring during sexual interaction.

The score rage of all scales (except for the GSS) runs from 0 to 100. The GSS differs with respect to the scoring procedure (see Vennix[17]) from the other scales used. The GSS score range runs from 5 to 34.

6.8.2.4 Design

Results derived from the participant population were compared to a control group to avoid disturbing effects of possible response shift bias.

Unfortunately this brings in other possible forms of bias e.g. selection bias. With regard to the most probably sources of selection bias preventive measures were taken. These sources of selection are: demographic differences, differences in having somatic complaints already existing before treatment that interfere with sexual functioning, and differences in sexual lifestyle.

- *Demographic differences.*

The IBCS is standardized for heterosexual Dutch men and women separately, who have a longlasting relation, up to 55 years of age and middle class. The experimental population consists of heterosexual women, with the exception of one, who have longlasting relationships.

The mean age in this population however is higher than in the control populations and it is hard to tell if there are essential differences in social economic class, but the factors of age as well as the factor of social position in our opinion are not important selective factors.

- *Somatic complaints.*

As having somatic complaints that interfere with having sexual intercourse do form an important selection source, only women who have not this type of problems are included in this part of the study.

- *Sexual lifestyle.*

In articles about the causes of carcinoma of the cervix a relation between the occurrence of cervical cancer and sexual lifestyle is often suggested. Having different partners and beginning to have intercourse at an early age would increase the risk of getting cervical cancer. The correlations found are weak though and are closely related with numerous other factors rendering the correlations rather spurious.

From the present epidemiological knowledge we conclude that our patient population does not essentially differ from the control group.

All in all, the existing differences between both populations are regarded as being too insignificant to have a disturbing effect on the internal validity of the research.

6.8.3 Results

Before discussing further results it was found remarkable that all respondents had sexual contact again with their partners regularly 6 months after finishing treatment. With the exception of one, all heterosexual women had sexual intercourse again.

Notwithstanding this, it further appears that treatment of cervical cancer leads to a considerable increase of dissatisfaction about sexlife in general.

No increase in discontent or complaints about the partner are heard, however. From the four investigated aspects of the psychosexual situation only "self-esteem as a sexual partner" shows a significant difference between experimental and control group. Women treated for cervical cancer have a significantly lesser positive view of themselves as sexual partner than women from the control group. On the other aspects of the psychosexual situation differences occur but no significant change could be found.

Table 1 Mean scores and standard deviations of general sexual dissatisfaction (IBCS6), relational sexual dissatisfaction (IBCS5), general satisfaction with sexual interaction with the partner (GSS), perception of mood disturbances (IBCS13), perception of physical condition (IBCS15), selfesteem as a sexual partner (IBCS16), appreciation of the partner as a sexual partner (IBCS17) for both the experimental patient population and the non-patient control group.

	experimental patient group (n=11) mean/st.dev.	non-patient control group (n=250) mean/st. dev.
IBCS6*	20.2/12.1	13.9/14.0
IBCS5	15.8/10.6	15.1/18.3
GSS	30.3/ 3.9	29.1/ 3.6
IBCS13	35.3/15.2	30.5/16.6
IBCS15	15.3/12.2	18.1/12.2
IBCS16*	17.2/ 0.5	12.0/12.3
IBCS17	8.9/14.3	10.4/12.6

* $p<.05$
IBCS: intimate bodily contact scale

6.8.4 Discussion

Except for the factor mood-disturbances increasing less than expected on the grounds of other publications[3] the results agree with those of other investigators.[2,10]

We would conclude that the sexual situation for women 6 months after treatment for cervical cancer is considerably less favourable than for the control group. Despite the fact that sexuality is valued a great deal less than before treatment, which could be seen as a drop in sexual interest, sexual interaction still occurs.

Post hoc analysis of the frequency of sexual interaction even showed no significant difference between patient and non-patient population.

This suggests that women who have recently been treated for cervical cancer are inclined to adapt to their partners rather than vice versa. Such behaviour possibly results as a consequence of a lowered self-esteem in combination with an increased dependency on the partner.

As an adaptive mechanism this situation could be looked upon as a type of "cognitive dissonance reduction". "Not feeling like sexual interaction" is incompatible with the female "love ethos".[18] As this love ethos for women includes not only the duty to give their partners love and attention, but also the preservation of harmony and a large dose of selfsacrifice, it is obvious that many women try to solve their emotional dilemma by reducing the value of their own point of view.

In this way the cognitive dissonance may be decreased and the feeling of well-being increased. The price paid for this though, is that their own point of view has to be undermined, which in turn may lead to another decrease in self-esteem. The 'blaming herself' instead of the partner for the discontent about sexuality could be explained in similar terms. Again there is a decrease in selfappraisal "it's not his fault, but mine", the price women have to pay to be able to maintain the higher valued interest: the love ethos.

Our findings agree with results of more general social sexuological research. Komter[19] found that about two thirds of the married women in her research wished for changes in their sexual lives, but only a small portion of them discusses them with their partners. De Bruijn[13] mentions, in reference to Vennix,[20] that almost 50% of Dutch women sometimes, often, or always have intercourse "without me really wanting it" (46%) or "while I don't feel like it" (44%). Here again women apparently adapt. Komter, as well as De Bruijn point out the important role of prevailing sexual norms guiding this behaviour. If we see behaviour as a result of the individual attitude as well as of social norms for women,[21] social norms in sexuality - in this case the love ethos - seem to carry most weight.

As a result of treatment for cervical cancer this mechanism seems to be strengthened. Influencing the social norms of patients therefore seems an important possibility to prevent a lot of potential dissatisfaction about sexuality after treatment for cervical cancer. If we realise that the social norms of treated women are for the most part influenced by the relevant attitude of others, in this case the partners, it is obvious that interventions on the individual level should be focussed at least also on the partners and that the individual attitude of the treated women themselves should be taken as the starting point.

Another, more system theoretical "solution" of the dilemma could be found in regulating the balance of power between partners, because it is the dependence of women in general and of women recently treated for cervical cancer in particular, that forces women to adapt to their partners.

Which approach is most effective in the prevention of sexual problems or more explicity which approach is preferable to both patients and their partners, will have to be investigated.

REFERENCES

1. MAGES, N.L. & MENDELSOHN, G.A. (1979) Effect of cancer on patient's life: a personological approach. In: G.C. Stone, F. Cohen & N.E. Adler (Eds.) Health Psychology. San Francisco, Jossey-Bass, pp.255-284.
2. ANDERSEN, B.L. & HACKER, N.F. (1983) Psychosexual adjustment of gynecologic oncology patients: a proposed model for future investigation. Gynecologic Oncology, 15, pp. 214-223.
3. MANTELL, J.E. (1983) The psychosocial and physiologic effects of invasive gynecologic cancers on female sexuality. In: L. Dennerstein & M. de Senarclens (Eds.) "The Young Woman" Psychosomatic Aspects of Obstetrics and Gynecology". Amsterdam, Excerpta Medica, pp. 398-408.
4. NEWTON, M. (1979) Quality of life for the gynecologic oncology patient. American Journal of Obstetrics & Gynecology, 15, pp. 866-869.
5. WALE, L. (1985) Sexuality and treatment of cancer. British Journal of Sexual Medicine, 4, pp.28-30.
6. ESCHENBACH, A.C. VON & SCHOVER, L.R. (1984) The role of sexual rehabilitation in the treatment of patients with cancer. Cancer, 54, pp. 2662-2667.
7. HERSCH, S.P. (1979) Views on the psychosocial dimensions of cancer and cancertreatment. In: P.J. Ahmed, G.V. Coelho & A. Kolker (Eds.) Toward a New Definition of Health. New York, Plenum Press.

8. CARENZA, L., STENTELLA, P., ALBANESE, M.G. & ETIOPE, S. (1982) Psychological and psychosomatic aspects in the sexual life of women following radical hysterectomy for carcinoma of the cervix. In: H.J. Prill & M. Stauber (Eds.) Advances in psychosomatic obstetrics and gynecology. New York, Raven Press, pp. 303-316.
9. ANDERSEN, B.J. & WOLF, F.M. (1986) Chronic physical illness and sexual behavior: psychological issues. Journal of Consulting and Clinical Psychology, 54, pp. 168-175.
10. BRANSFIELD, D.D. (1984) Psychosexual functioning after treatment for gynaecologic malignancy. New York, Yeshiva University.
11. BOS, G. (1985) Sexuality of gynecologic cancer patients: Quantity and Quality. In: Van E.V. Hall (Ed.) Psychosomatic Obstetrics and Gynecology. Leiden: University of Leiden, pp. 125-135.
12. JAYNE, C. (1981) A two-dimensional model of female sexual response. Journal of Sex and Marital Therapy, 7, pp. 3-30.
13. BRUIJN, G.M. (1985) Vrijen met jezelf in een relatie. In: J.A. Schraag (Ed.). Libidoproblemen bij man en vrouw. Leiden, University of Leiden, pp. 169-180.
14. HELSON, H. (1964) Adaptation-level theory: an instrumental and systematic approach to behavior. New York, Harper.
15. FRENKEN, J. (1976) Afkeer van seksualiteit. Deventer, Van Loghum Slaterus.
16. GORDON, S. In: J.F.A. Pruijn, H.W. van den Borne Lotgenoten-contact bij kankerpatiënten. Assen/Maastricht: Van Gorcum.
17. VENNIX, P. (1983) De ILKS-gedachte". Zeist, NISSO.
18. WEEDA I. (1986) Over liefde gesproken. Houten, De Haan.
19. KOMTER, A. (1985) De macht van de vanzelfsprekendheid. 's-Gravenhage, Vuga.
20. VENNIX, P. (1983) Ontwikkelingen in heteroseksuele relaties. Zeist, NISSO.
21. FISHBEIN, M. & AJZEN, I. (1975) Attitude, attention and behavior: an introduction to theory and research. Reading (Mass.), Addison- Wesley.

6.9 Prognostic variables for sexual functioning after gynaecological cancer treatment*

6.9.1 Introduction

In the literature on sexual functioning after gynaecological cancer treatment by the various authors a large variety of variables is presented as "prognostic".[1] The relevance of the identification of so-called prognostic variables is twofold. In the first place these variables give insight in the mechanisms that elicit and control sexual behaviour after gynaecological cancer treatment. In the second place data on these mechanisms could provide guidelines for health care interventions in order to restore or prevent sexual functioning morbidity after gynaecological cancer treatment.

Based on an extensive review of the literature, Weijmar Schultz et al.[1] identified the following variables, clustered into four categories, that could be identified as prognostic:

- partner related variables, e.g. availability, attitude, health and length of relationship;
- health-care-related factors, such as patient education and/or counseling;

* H.B.M. Van de Wiel, W.C.M. Weijmar Schultz & J. Bouma (1990) Submitted for publication.

- physical factors, such as oestrogen deprivation, postcoital bleeding, vaginal shortening, stenosis or the magnitude of surgical intervention;
- psychological variables, such as body image, pre-treatment libido level and sex-role rigidity.

The same review, however, also made clear that empirical evidence for the predictive validity of these variables is very scarce. The purpose of this article is to test empirically the relevance of these prognostic variables and to discuss their contribution to the process of understanding sexual functioning morbidity after gynaecological cancer treatment.

6.9.2 Methods

6.9.2.1 Design

In order to test the predictive validity of the prognostic variables a "limited" prospective correlational design was used. The prospective design is "limited" because the initial assessment of the patient groups occurred on admission. A real pre-post design demands an initial assessment before cancer signs and symptoms. This is virtually impossible because random assignment to "cancer" and "noncancer" conditions is not possible. Retrospective evaluation of sexual functioning before the onset of cancer signs and symptoms was carried out at the first assessment, i.e. during admission for cancer diagnosis and treatment.

The longitudinal aspect included, apart from the pre-treatment assessment, an assessment at 12 months post-treatment. This point in time to evaluate sexual functioning morbidity was chosen here because studies of patients with carcinoma of the cervix[2] and of breast cancer patients[3,4] have indicated that significant disruption of sexual functioning appeared within the first year post treatment.

6.9.2.2 Subjects

Before subjects were recruited, women were excluded from participation according to the following criteria:

- age < 16 or > 70 years
- history of psychiatric or somatic disorder that might interfere with the sexual relationship.

No restrictions were made towards sexual preference or marital status. Partners were invited to participate in the study.

The voluntary nature of participation was stressed and it was made explicitly clear that it would be possible to withdraw from the research programme at any time. Therefore no pressure was set on those who immediately refused to participate nor on those who ended their participation during the 24 months of the study, although this latter procedure made analysis of drop-outs impossible.

The following groups of gynaecological cancer patients were included in this study:

Vulvar cancer. A consecutive group of 13 women and their partners were invited to participate in the research project. Three couples did not feel capable to participate because of emotional reasons. Response rate: 77%. Because not all questionnaires were returned and some, although returned, were inadequately filled in this study only 7 cases could be evaluated.

Cervical cancer. Seventy-two women and their partners were asked to participate. Eighteen couples did not feel capable to participate. Response rate: 75%.

Here also not all participants provided adequate information. Twelve participants had to leave the study because of medical reasons (e.g. recidive or hospital admission for other reasons), 14 withdrew completely from this study and 3 only took part in another part of the research project. In the end only 25 cases could be used for evaluation in this study.

The total group of participants in this study, patients treated for vulvar cancer or treated for cervical cancer, was 32 patients with gynaecological cancer.

6.9.2.3 Criterium and predictor variables

Because this study makes part of a larger research project on sexual functioning after gynaecological cancer treatment and Dutch questionnaires were used to operationalize most of the criterium and predictor variables, a short description is provided here of the used questionnaires and their theoretical background. The assessed criterium and predictor variables are followed in the text by their actual operationalization.

6.9.2.4 Criterium variables

It has been discussed before that measuring sexual functioning by means of a single behavioural measure (e.g. intercourse frequency), an indication of responsiveness (e.g. presence or absence of orgasm), or an estimation of global satisfaction is not a valid way to conceptualize sexual functioning.[5] Therefore we chose for a multidimensional approach, in which motivational, behavioural and emotional variables were used as defined in terms of the Social Learning Theory of Rotter.[6] Besides, sexual arousability was measured in terms of the sexual response as defined by Masters & Johnson.[7]

To obtain reliable as well as valid data, the decission was made to use self-report questionnaires as the main source of data gathering. Nearly all dependent variables were operationalized for theoretical and practical reasons by means of the Intimate Bodily Contact Scale (IBCS) of Vennix.[8] Theoretically because this scale is based on Rotter's theory on social learning, which also formed the theoretical framework for the entire research project, and practically because in the Netherlands it is the only well investigated and psychometrically funded scale available. The IBCS is an extensive self-report questionnaire, which contains 22 subscales covering various detailed aspects of sexual functioning. The subscales are standardized for heterosexual Dutch men and women separately and the internal consistency is generally high. For a more detailed description of the concept and development of this scale we refer to Vennix.[8-9]

Although most variables could be operationalized by means of the IBCS, a number of variables could not. For these remaining variables special scales were designed, marked with an asterisk, or existing other scales were adapted. For these scales norms for the female population as well as the reliability scores were developed during this study. A detailed description of the newly developed questionnaires is provided elsewhere (Chapter 6).

Sexual motivation and overt sexual behaviour; In terms of Rotter's theory on social learning, the subject's experience with sexual motivation and overt sexual behaviour can be "ideal" and can be "real":

Ideal experiences meet the subject's aim in sex matters. These aims can be subdivided into two categories: 1. appreciation for sexual arousal and 2. appreciation for intimacy. Sexual arousal includes sexual arousal-inducing-behaviour as well. Intimacy includes intimacy-inducing-behaviour as well. In this way four different aspects of sexual motivation are distinguished:

- appreciation of behaviour-inducing-sexual arousal
- appreciation of behaviour-inducing-feelings of intimacy
- appreciation of sexual arousal
- appreciation of intimacy.

Real experiences are the actual behavioural and emotional results of the sexual interaction. Again four different variables can be identified:

- freqency of behaviour-inducing-sexual arousal
- frequency of behaviour-inducing-intimacy.
- frequency of sexual arousal
- frequency of intimacy

Operationalization:

Ideal experiences:

- appreciation of sexual arousal	IBCS-8
- appreciation of intimacy	IBCS-7
- appreciation of behaviour-inducing-sexual arousal	IBCS-22
- appreciation of behaviour-inducing-feelings of initimacy	IBCS-21

Real experiences:

- frequency of sexual arousal	IBCS-2
- frequency of intimacy	IBCS-1
- freqency of behaviour-inducing-sexual arousal	IBCS-20
- frequency of behaviour-inducing-intimacy	IBCS-19

Sexual (dis)satisfaction; According to the social learning theory, sexuality can only be evaluated in subjective terms because there is no such thing as "objective sexuality". Therefore evaluation of sexual functioning was operationalized in terms of personal subjective experiences. Only the individual subject is able to judge his or her sexual functioning as satisfying or dissatisfying.

An important problem in quality of life research is the amount of restriction in the domain people are asked to evaluate. In this case sexuality can be evaluated in a strict sense, e.g. "If you only have to look at yourself at the present time how satisfied are you with your sexual life in a strict sense?". However, sexuality can also be evaluated in a more broad sense, e.g."Seen in the light of everything what has happened the last months, how satisfied are you with your sexual life in general?".

For practical reasons and because we expected that in the strict context of sexuality changes would be most closely connected with sexual dissatisfaction, the term "sexual dissatisfaction" was chosen as the first measure of importance for sexual

functioning in the study. Given the important component of relatedness in (female) sexuality a distinction is made between sexual dissatisfaction from the personal individual perspective, i.e. the "personal sexual dissatisfaction" and "sexual dissatisfaction within the context of partner relationship", i.e. the relational sexual dissatisfaction.

With regard to our question to evaluate sexual functioning in a more broad sense "general sexual satisfaction" was taken as a measure.

Operationalization:

- personal sexual dissatisfaction	IBCS-6
- relational sexual dissatisfaction	IBCS-5
- general sexual satisfaction	IBCS-GSS

The sexual response; The capacity to experience and induce feelings of sexual excitement and orgasm is defined by Masters and Johnson[7] as the sexual response. In this study three distinct aspects of the sexual response cycle were investigated separately, i.e. genital feelings of sexual arousal, perception of feelings of orgasm and the capacity to induce sexual arousal and orgasm.

Operationalization:

- genital sensations during arousal	GAS-GSSUM *
- orgastic sensations	GAS-OSSUM *
- ability to induce sexual arousal and orgasm	GAS-CAPSUM *

6.9.2.5 Predictor variables

Based on the literature[1] the following four categories of predictor variables could be identified:

- partner related variables, e.g. availability, attitude, health and length of relationship;
- health-care-related factors, such as patient education and/or counseling;
- physical factors, such as dyspareunia, oestrogen deprivation, postcoital bleeding, vaginal shortening, stenosis or the magnitude of surgical intervention;
- psychological variables, such as body image, pre-treatment libido level, age and sexe role rigidity.

Most of these variables could be operationalized in terms of psychometric scales, thereby making correlational analyses possible. Some variables however, e.g. patient education and counseling, could not be operationalized at all.

Again a short introduction and description of each variable is provided here, followed by its actual operationalization.

6.9.2.6 Partner related variables

Although availability of a partner was no criterium to participate in our study, all women who did participate had a more or less stable relationship with a partner. Therefore this variable could not be investigated in this study.

* The scales marked with an asterisk were specially designed for this study. The abbreviations refer to the sumscore of the measured concept, e.g. GSSUM is the sumscore of all items covering genital sensations during sexual arousal.

The variable "attitude" of the partner was not included in this study because a far more direct variable was available i.c. the patient's appreciation of the partner and the relationship: *Appreciation of the partner;* because the quality and length of the partner relationship are mentioned as predictor variables both factors were measured. The quality was measured in terms of appreciation of the relationship in general and the partner as a sexual partner, the length of the relationship in terms of duration in years.

Operationalization:

- appreciation of the partnerrelationship in general (before treatment)	IBCS-AP
- appreciation of the partner as a sexual partner (before treatment)	IBCS-17
- length of partner relationship	Demographical Checklist

6.9.2.7 Health-care-related factors

In the literature it is hypothesized that the presence of myths and misinformation on sexual matters may play an interfering role with sexual rehabilitation. However, as it seemed unrealistic to measure "knowledge" of sexual functioning in general and after gynaecological cancer in particular, this variable was not measured. To rule out the influence of this factor as much as possible, it was decided to provide all participating women and their partners the same, detailed information. Therefore an information booklet about gynaecological cancer treatment was written that included information about the sexual consequences of the disease and its treatment. It was assumed that, by giving access to this information, in addition to verbal information, all participants in the research project would receive more or less the same amount of information.

6.9.2.8 Physical variables

In the literature a number of physical variables are presented as predictor variables such as oestrogen deprivation, postcoital bleeding, vaginal shortening, stenosis and magnitude of surgical intervention. In our sample oestrogen deprivation, postcoital bleeding and stenosis hardly occurred so these variables had to be left out of the analyses. The influence of the magnitude of surgical intervention has been discussed elsewhere.[10]

Furthermore it is important to notice that dyspareunia before treatment was scarce in our population and that after treatment dyspareunia can not be treated as a predictor variable because it could be a criterium variable as well. All by all two physical variables were investigated in this study: vaginal shortening and loss of genital sensitivity after surgery. The first variable was measured by means of a medical checklist and during medical examination with the help of pelotes. The second variable was measured by means of a psychophysiological assesment procedure which is described elsewhere in detail.[11]

Operationalization:

- vaginal shortening	Medical Checklist and pelotes
- genital sensitivity	Psychophysiological Assessment

6.9.2.9 Psychosexual variables

In the literature on sexual functioning after gynaecological cancer treatment, except for past experiences, hardly any pre-treatment psychosexual variables are marked as prognostic variables for post treatment sexual functioning. Based on literature on sexual functioning in general, we added some new psychosexual variables to this study, which we hypothesized to be of importance for predicting post-treatment sexual morbidity. This lead to the inclusion of the following variables: sexe role rigidity, negative expectations on post-treatment sexual functioning, age and past experiences or personal sexual history.

Sexe role rigidity; Given the physical changes induced by the treatment, we thought that the flexibility in sexe role behaviour could be of importance for post treatment sexual functioning. The concept of sexe role rigidity is according to Vennix[8] closely connected to the concept of self confidence and self assurance.

Operationalization:

- self-confidence in social situations	IBCS-P1
- self-assurance	IBCS-P2.

Negative expectations; According to the Social Learning Theory people incorporate their (new) observations into (old) ideas and opinions. Therefore we thought it would be interesting to find out whether a relation could be found between pre-treatment expectations about sexual functioning after treatment and the actual post-treatment sexual experiences.

Operationalization:

- negative expectations	NEGEXP *.

Past experiences; A special type of personality variable is one's personal sexual history. According to the Social Learning Theory one's present sexual behaviour is strongly determined by earlier sexual experiences. Because no real prospective design could be used this variable could only be operationalized by using retrospective reports of the patients.

Operationalization:

- frequency of sexual arousal (retrospective)	IBCS-2
- frequency of intimacy (retrospective)	IBCS-1
- freqency of arousal-inducing-behaviour (retrospective)	IBCS-20

- frequency of intimacy-inducing-behaviour (retrospective) — IBCS-19.

Age; A variable which is closely related to past psychological experiences at the one hand and to physical processes at the other hand is age.

Operationalization:

- age — Demographic Checklist.

6.9.2.10 Statistical analyses

The predictive validity of each variables was expressed and analysed in terms of Pearson correlations, using SPSS-X procedures.[12]

In the tables only the significant (p=<.05) correlations are depicted.

6.9.3 Results

No significant predictor variables could be detected for the criterium variable "general sexual satisfaction" (table I). Both operationalizations of "sexual dissatisfaction" however, did reveal a significant correlation with the frequency of sexual arousal as well as with the frequency of sexual arousal-inducing-behaviour before treatment. The way patients are dissatisfied with their sex life after treatment seems te be best predicted by the sexual activity before treatment.

Table I Correlations of the criterium variable "sexual (dis) satisfaction at 12 month post treatment" operationalized in terms of sexual dissatisfaction (IBCS-6), sexual relational dissatisfaction (IBCS-5) and general sexual satisfaction(IBCS-GSS) with the following predictor variables: selfesteem as a sexual partner before treatment (IBCS-17), the frequency of experienced feelings of sexual arousal before treatment (IBCS-2) and the frequency of sexual arousal inducing behaviour before treatment (IBCS-20)

	IBCS-6	IBCS-5	IBCS-GSS
Predictor variables			
IBSS-17	.47	—	—
IBCS-2	-.50	-.45	—
IBCS-20	-.50	-.42	—

IBCS: intimate bodily contact scale

Sexual motivation seems best predictable by the patient's age. However, a distiction must be made between the motivation for sexual arousal, which is more positively correlated with age, and the motivation for intimacy, which is on the contrary negatively correlated with age. The aspect of intimacy seems be to more important to younger women than to elderly. Furthermore it appears that the post-treatment libido correlates quite high with pre-treatment sexual activity.

Table II Correlations of the criterium variable "sexual motivation at 12-month post-treatment" operationalized in terms of appreciation of experienced feelings of sexual arousal (IBCS-8), appreciation of experienced feelings of intimacy (IBCS-7), appreciation of sexual arousal-inducing-behaviour (IBCS-22), and appreciation of intimacy-inducing-behaviour (IBCS-21) with the following predictor variables: age (AGE), the frequency of intimacy-inducing-behaviour before treatment (IBCS-19) and the frequency of sexual arousal-inducing-behaviour before treatment (IBCS-20)

	APPRECIATION OF			
	sexual arousal		intimacy	
	IBCS-8	IBCS-22	IBCS-7	IBCS-21
Predictor variables				
AGE	.45	—	-.41	—
IBCS-19	—	—	—	.52
IBCS- 20	—	.55	—	—

IBCS: intimate bodily contact scale

Table III Correlations of the criterium variable " sexual behaviour at 12-month post-treatment" operationalized in terms of frequency of experienced feelings of sexual arousal (IBCS-2), frequency of experienced feelings of intimacy (IBCS-1), frequency of sexual arousal-inducing-behaviour (IBCS-20), and frequency of intimacy-inducing-behaviour (IBCS-19) with the following predictor variables: age (AGE), the frequency of experienced feelings of intimacy before treatment (IBCS-1),the frequency of experienced feelings of arousal before treatment (IBCS-2), the frequency of intimacy-inducing-behaviour before treatment (IBCS-19), the frequency of sexual arousal-inducing-behaviour before treatment (IBCS-20), and the general appreciation of the partner before treatment (IBCS-AP)

	FREQUENCY OF			
	sexual arousal		intimacy	
	IBCS-2	IBCS-20	IBCS-1	IBCS-19
Predictor variables				
AGE	-.45	-.44	—	—
IBCS-1	.40	.42	.43	—
IBCS-2	.68	.49	—	—
IBCS-19	—	—	—	.61
IBCS-20	—	.80	—	.44
AP	—	—	—	.69

IBCS: intimate bodily contact scale

Off all criteria sexual behaviour shows the most highest correlations with predictor variables (table II and III). Age seems to be important especially as a predictor of sexual behaviour in terms of sexual arousal, which is more experienced by younger women than by elderly women. High correlations are found for pre- and post-frequencies of sexual behaviour. The appreciation of the partner before treatment seems to be only an adequate predictor of post-treatment sexual behaviour which is directed towards inducing intimacy.

The sexual response seems to be hardly predictable by any pre-treatment variable (table IV). Significant correlations could only be detected for the genital sensations during sexual arousal with the frequency of experienced sexual arousal before treatment and with the frequency of initimacy-inducing-behaviour before treatment. Orgastic sensations and the capacity to induce sexual arousal and orgasm seem not to be predictable by the investigated pre-treatment variables.

Table IV Correlations of the criterium variable " sexual response at 12-month post-treatment" operationalized in terms of frequency of experienced feelings of genital sensations during sexual arousal (GSSUM), frequency of experienced orgastic feelings (OSSUM), the capacity to induce sexual arousal and orgasm (CAPSUM) with the following predictor variables: the frequency of experienced feelings of arousal before treatment (IBCS-2) and the frequency of intimacy inducing behaviour before treatment (IBCS-19)

	SEXUAL RESPONSE		
	GSSUM	OSSUM	CAPSUM
Predictor variables			
IBCS-2	.42	—	—
IBCS-19	.41	—	—

IBCS: intimate bodily contact scale

6.9.4 Discussion

Although on this relatively small number of observations only limited and cautious conclusions can be drawn some interesting results can be reported.

With regard to sexual (dis)satisfaction it is remarkable that no predictor variables could be identified for general sexual satisfaction, while sexual dissatisfaction (personal as well as relational) after treatment correlated quite high with pre-treatment sexual behaviour (both: r= .50). This discrepancy in predictability between sexual dissatisfaction and general sexual satisfaction could be caused by the fact that general sexual satisfaction, in contrast to sexual dissatisfaction, refers to a more broad psychological domain, covering a number of interdependent subdomains, thus making it harder to predict.

Sexual dissatisfaction appeared to be best predictable by past sexual experiences. Post-hoc analysis revealed that this correlation is mainly based on the group of patients who's sexual interaction was not very satisfying before treatment. In the group who's satisfaction score was above the median no significant correlation could be detected.

Sexual motivation after treatment could partly be predicted by age, which is in fact not very suprising and has been mentioned in the literature before.[13-14] More interesting is the fact that younger women tend to emphasize the intimacy aspect, where older women are more inclined towards the aspect of sexual arousal. This phenomenon may reflect a cultural change in giving meaning to sexuality during the last decades. Furthermore past sexual experiences showed a high correlation with post-treatment motivation. In other words, the more sexual interaction in the past has led to feelings of initimacy and/or sexual arousal, the more patients are motivated to resume sexual interaction after treatment again. This confirms one of the basic assumptions of the Social Learning Theory as formulated by Rotter[6] namely that people will be motivated for certain types of behaviour only if they have the idea that that specific type of behaviour will lead to desirable outcomes, i.c. feelings of intimacy and arousal.

Pre- and post-treatment overt sexual behaviour directed towards feelings of sexual arousal, e.g. having coitus, (mutual) masturbation and/or oral sex and pre- and post-treatment intimacy-inducing-behaviour, e.g. cuddling and hugging, hand and eye contact, correlated very high (r=.80 and r=.60 respectively). This means that the patterns to express sexual and intimate feelings are very strongly rooted in the individual's way of life and is hardly changed by external influences, i.c. not even by very interfering disease or medical treatment.

As could be expected there is a negative correlation between age and the frequency of sexual behaviour directed towards feelings of arousal. Furthermore the results showed a high positive correlation between the pre-treatment appreciation of the partner in general and post-treatment frequency of feelings of intimacy.

The sexual response after treatment appeared to be hardly predictable, only genital feelings of arousal were correlated with past experiences. The physical variables which were included in the study, i.e. genital sensitivity threshhold and length of the vagina, did not seem to be of any predictive importance at all.

In summary, we may conclude that overt sexual behaviour after treatment can be predicted quite acurately by past sexual experiences i.e. pre-treatment sexual behaviour. Other aspects of sexual functioning like satisfaction, motivation and sexual response are less predictable. This indicates that the patterns to express sexual and intimate feelings are very strongly rooted in the individual's way of life. Perhaps it is even better to speak of the individual's social life because, even if the individual's psychological and physical situation is severely disrupted, the patterns of sexual behaviour remain the same. These results are in agreement with earlier results, indicating relatively little changes in sexual satisfaction, motivation and behaviour while relatively large changes in the sexual response cycle occurred.[10,14-17] Both phenomena can be easily explained if we take in account that women regard sexual situations in the first place as "social" situations; feelings of closeness to and intimacy with the partner are of more importance than sexual arousal, which depends more on the perception of genital sensations and physiological functions in the genital area. From other research on human inference it is known that people in social situations are more likely to rely on their theories and expectations about a certain situation than on the actual data themselves.[18] Here therefore, it could be expected that the way these patients perceive and interpretate sexual situations and

stimuli, in general seems to remain the same after treatment as before, even though large physical and psychological changes did occur and are perceived. This idea suggest priority of psychological variables over physical variables in this particular situation. This of course cannot be deduced from the data of this study on predictability alone but is in fact in agreement with the results of an earlier study in which no significant differences could be detected in sexual functioning, except for the sexual response, between hysterectomy patients on benign and on malign indication before and after treatment.[10]

Although these results are interesting from a scientific point of view because they give insight in the mechanisms that regulate sexual functioning, they are a little bit disappointing with regard to the possibilities of health care interventions. The main predictors, past sexual experiences and age, are beyond the scoop of direct intervention because they can only be influenced by long term macro-social processes, leaving them here as "risk-indicators" only. This may sound a little pessimistic but it has to be kept in mind that in this study only the predictive validity of a number of variables was evaluated. This does not mean that post-treatment sexual functioning is not regulated by other, perhaps more controlable, factors.

REFERENCES

1. WEIJMAR SCHULTZ, W.C.M., BRANSFIELD, D.D., WIEL, H.B.M. VAN DE & BOUMA, J. (1991) Sexual outcome following female genital cancer treatment; a critical review of methods of investigation and results. Accepted by Sexual and Marital Therapy.
2. VINCENT, C.E, VINCENT, B., GREISS, F.C. & LINTON, E.G. (1975) Some marital-sexual concomitants of carcinoma of the cervix. Southern Medical Journal, 68, pp. 552-558.
3. MAGUIRE, G.P., LEE, E.G., BEVINGTON, D.J., KUCHEMANN, C.S., CRABTREE, R.J. & CORNELL, C.E. (1978) Psychiatric problems in the first year after mastectomy. British Medical Journal, 1, pp. 963-965.
4. MORRIS, T., GREER, H.S. & WHITE, P. (1977) Psychological and social adjustment to mastectomy. Cancer, 40, pp. 2381-2387.
5. ANDERSEN, B.L., ANDERSON, B. & DEPROSSE, C. (1989) Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. Journal of Consulting and Clinical Psychology, 57, pp, 683-691.
6. ROTTER, J.B. (1954) Social learning and clinical psychology. Englewood Cliffs, N.J., Prentice-Hall.
7. MASTERS, W.H. & JOHNSON, V.E. (1966) Human Sexual Response. Boston, Little Brown.
8. VENNIX, P. (1983) De ILKS gedachte. Zeist, NISSO.
9. VENNIX, P. (1989) Seks en sekse. Delft, Eburon.
10. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE & BOUMA, J. (1990) Psychosexual functioning after the treatment of cancer of the cervix, a comparative and longitudinal study. Accepted by The International Journal of Gynaecologic Oncology.
11. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, KLATTER, J.A., STURM, B.E. & NAUTA, J. (1989) Vaginal sensitivity to electric stimuli: theoretical and practical implications. Archives of Sexual Behavior, 18, pp.87-95.
12. SPSS-X User's guide (1983). New York, McGraw Hill.

13. SEWELL, H.H. & EDWARDS, D.W. (1980) Pelvic genital cancer: body image and sexuality. Frontiers of Radiation Therapy and Oncology, 14, Basel, Karger S, pp.35-41.
14. WEIJMAR SCHULTZ, W.C.M., WIJMA, K., WIEL, H.B.M. VAN DE, BOUMA, J. & JANSSENS, J. (1986) Sexual rehabilitation of radical vulvectomy patients, a pilot study. Journal of Psychosomatic Obstetrics and Gynaecology, 5, pp. 119-126.
15. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G. & BOUMA, J. (1988) Sexual functioning following treatment of cervical carcinoma. European Journal of Gynaecologic Oncology, 9, pp. 275-281.
16. WIEL, H.B.M. VAN DE, WEIJMAR SCHULTZ, W.C.M., HALLENSLEBEN, A., THURKOW, F.G., BOUMA, J. & VERHOEVEN, A.C. (1990) Sexual functioning of vulvacarcinoma patients. Sexual and Marital Therapy, 5, pp. 73-82.
17. WEIJMAR SCHULTZ, W.C.M., WIEL, H.B.M. VAN DE, BOUMA, J., JANSSENS, J. & LITTLEWOOD, J (1990) Psychosexual functioning after the treatment of cancer of the vulva; a longitudinal study. Cancer, 6, pp. 402-407.
18. NISBETT, R.E. & ROSS, L. (1980) Human inference: strategies and short- comings of social judgment. Englewood Cliffs, N.J., Prentice-Hall.

6.10 Retrospective methodological remarks and summary of the overall conclusions

6.10.1 Retrospective methodological remarks

Like in every other study, a number of reasons can be put forward why the results of this (entire) study are limited in their generalizability. The most important methodological shortcomings will be discussed here briefly before a summary of conclusions is given.

Because all measurements used demonstrated to be sufficiently reliable, here only the issue of validity will be discussed, in which a distinction is made between internal and external validity.

Internal validity

Number of patients Although the number of patients investigated is few and conclusions with regard to differences between groups can only be drawn cautiously, the fact that a consistent pattern emerges from the results make them more solid.

Retrospectivity Part of the information obtained, i.c. data from the first pre-treatment assessment, is retrospective. Although this problem could not be avoided for practical reasons, comparison of our patient populations with a control group of healthy women gave insight in the quality and quantity of changes in looking back on sexual functioning after being faced with the diagnosis gynaecological cancer. The effect of this part of the treatment was taken into account in discussing the results.

Another point of concern here is that gynaecological cancer is associated with short-term (cervical cancer) and long-term (vulvar cancer) symptoms before diagnosis. These symptoms may have already affected sexual functioning. However, there was no difference between the sexual functioning of the age-matched nonpatient

control group and the patient group before the gynaecological cancer treatment despite the patient group's multiple physical complaints. Therefore no special notice had to be taken from this phenomenon.

The Hawthorne effect A detailed assessment of a so important part of life as sexual functioning, inevitably has an effect on the participants in the study. Therefore the question rises whether there are any signs that this particular group of patients is incompatible with other patient groups which did not participate in a study like this. Because no significant differences could be traced between our cervical cancer patient population which took part in the entire research protocol (four assessments) and a comparison group of women treated in a similar way but who's sexual functioning was assessed only once, this seems unlikely.

Finally, also a number of phenomena can be mentioned which can be regarded as indications that the methodological level of this study was sufficient to make conclusions justified. In the first place there is the fact that the internal consistency of our results is rather high. Data gathered by interviews are confirmed by data from self-report questionnaires and for all treatment populations more or less the same rehabilitation pattern is found, which is so typical for rehabilitation after a traumatic experience. In the second place because a number of different convergent measurements, which have all demonstrated to be highly reliable, where used to operationalize aspects of sexual functioning. Again, the results of all these measurements lead to more or less similar results and conclusions. This means that, to our opinion, the internal validity can be regarded as adequate.

External validity

The main problem threatening the generalizability of our results lies in the external validity. Is there a selection bias which makes that our results are only worthwile for our participants, a Dutch population, treated and taken care of in the University Hospital Groningen between 1984 and 1989 ?

Although this question is very hard to answer within the range of one research project alone, again the answer seems to be no. The most convicing argument is the fact that our results are confirmed by other researchers, independant from our activities and in other countries.

In general therefore, we do think that our results are worthwile to be published and may serve as guidelines for future research and practical clinical care. This is particularly the case for the overall patterns of sexual functioning after gynaecological treatment, which will be summarized here once more.

6.10.2 Summary of overall conclusions

Vulvar cancer

Based on the results of the self-report questionnaires, it was concluded that severe damage to sexual functioning in general could be confirmed, particularly at the 6-month assessment. Nevertheless, in spite of a persistent, marked, deterioration in the perception of genital symptoms of sexual arousal, all women who were sexually

active before treatment had resumed their sexual activities within 1-year post-treatment. In comparison with the pre-treatment situation and the control group, no clear difference in general satisfaction with sexual interaction with the partner was found.

This remarkable difference between deteriorating effects on specific parts of sexual functioning and the relatively stable general satisfaction with sexual life as measured by self-report questionnaires, was confirmed by the results of the interviews.

Cervical cancer

The results make it clear that gynaecological cancer patients face stressful, even traumatic events and show deterioration in their sexual functioning, even 1 and 2 years after treatment. However, despite persisting poor sexual response and annoying physical complaints, they attempt and manage to maintain a sexual life .

Determining variables

For the sexual rehabilitation process after vulvar cancer as well as for cervical cancer, psychological factors seem to play the most important role. Before and after treatment, motivation for sexual expression, closely related to the extent of mutual affection felt, seems to be the most important factor for sexual rehabilitation. At the same time, the data suggest that a woman's motivation for, and satisfaction with sexual interaction with her partner is not limited to the experience of sexual arousal. A whole range of other emotions may be involved. In this current study the affection for the partner, the wish to do something in return, but also the fear of losing the partner seem to play a crucial role in the motivation for sexual rehabilitation.

The process of sexual rehabilitation itself therefore, seems to be guided by a more general and higher order process, probably the striving for balance in the relationship. From the viewpoint of the script theory the sexual script can be seen as a specific type of the female social script, described by Weeda as the love ethos. The need to cling to this kind of scripts seems to be enlarged by such a traumatic experience as gynaecological cancer. The results indicate that more or less the same happens for partners, but here the typical 'male' version of the social and sexual script is found.

PART III

PRACTICAL IMPLICATIONS

Chapter 7

7.1 Future directions

Now the impact of gynaecological cancer treatment on sexual functioning seems well established, the time has come to raise some more fundamental questions. These questions can be categorized as methodological, psychophysiological and psychological issues.

Methodology; although the general outlines of sexual functioning after gynaecological cancer treatment can be made clear by using existing measures, it remains necessary to develop new, more refined measures specifically designed for women with cancer.

Psychophysiology; what still remains unclear are the exact psychophysiological interactions that induce the sexual response for women in general and for women treated for gynaecological cancer in particular. More research is needed. Psychophysiogical studies on the sexuality of women treated for benign or malignant gynaecological disease might yield more knowledge about deterioration of the sexual response. In the future psychophysiologic techniques might be important intervention tools in psychosexual counseling programmes.

Psychology; because psychological variables seem to be the most determining factors for (sexual) rehabilitation, more information is needed to be able to make use of these variables in order to improve the (sexual) rehabilitation process after gynaecological cancer treatment. Given the overall importance of social roles as guidelines for social behaviour, it seems justified to emphasize research on not only sexual scripts but also on patient scripts as well as physician scripts.

7.2 Some guidelines to help patients and partners cope with sexual problems after treatment of gynaecological cancer

The adaptation of gynaecological cancer patients and their partners to a new (sexual) life after cancer treatment, often appears to be a difficult and time-consuming process. This process has the most optimal chance of being successful if the relationship before treatment was satisfying and if, afterwards, an optimal relationship can be established between the professional care provider and the couple concerned. It is the responsibility of the professional to facilitate the adjustment process by creating productive conditions for change, especially with regard to communication between all parties and by providing information. It is the responsibility of the couple involved to decide whether they are able and willing to accomplish this demanding task.

As we saw in chapter 4 and 6 a variety of somatic and psychological disturbances may arise as a result of gynaecological cancer (treatment) and may have their impact on sexuality. The consequences of gynaecological cancer and its treatment therefore often force patient and partner to redefine their sexual relationship, to explore the

remaining possibilities with regard to sexual behaviour and, if necessary, to create new forms of sexual interaction. Adequate communication is a prerequisite for this problem solving process.

Another important issue was the supply of information about the disease, in this case gynaecological cancer, and its various consequences. The confrontation with gynaecological cancer often leaves a person with the feeling of not being able to control his/her life anymore. By giving information, however threatening or painful that may be to the patient initially, the physician provides his patient with possibilities to regain control.

Some authors therefore suggest that sexual matters should be brought up at all stages of the disease and its treatment. At the same time though, we would like to stress that the information presented (about sexuality or other subjects) should agree with the patient's needs at that specific moment and that the patient's needs should not be assessed by the physician, but should be expressed by the patient herself (and her partner) explicitly. The physician can (only) help the couple in doing so by asking specific questions, by confronting them with his impressions and by presenting his own point of view, for instance "that the information is important".

Based on these assumptions the following practical guidelines are recommended:

- the professional should attempt to involve the patient's partner as much as possible and as soon as possible and during all treatment phases, except when the partner-relationship is seriously hampered by intra- or interpersonal pathology;
- the professional should communicate open and clearly and at the proper time, in the proper place and thereby serve as a "model" for the couple;
- the professional should provide clear and explicit information and take the initiative to do so. In short:
  - speak in specific terms instead of being vague,
  - do not be a thought-reader,
  - use direct language;
- the professional should encourage the patient and the spouse to communicate in an open and clear manner;
- the professional should refrain from thinking or acting on behalf of the patient or her spouse, thereby taking over their responsibilities (for instance: trying to tone down "bad news messages" in order to prevent the patient from becoming anxious);
- the professional should carefully examine his own attitudes and feelings towards sexuality. If he feels uncomfortable in discussing sexual issues, he should (know where to) refer the patient and her partner;
- the professional should avoid pushing the patient and her partner into changing their interactions. He should try to follow the couple's pace of adjustment:
  - by accepting the couple's rejection to discuss a specific topic,
  - by making that rejection explicit by ventilating his observations or impressions or by asking for clarification,
  - by reassuring the couple that it is normal for such an adaptation process to take some (or even much) time,

- by refraining from "problem solving", although presenting information about various alternatives (for instance in sexual interaction),
- by constantly checking on what specific information the couple needs at various stages of the treatment and to what extent they wish to have the information provided, leaving the decision up to the patient and her partner;

- the professional should be capable of accepting the fact that not all couples can or wish to be helped, no matter how hard he tries. Paradoxically, it may even be more helpful to such couples if the professional were to stop attempting to help them and, instead, express his own feelings of powerlessness regarding the couple's problems or the way in which these are presented to him. The couple might then become motivated to take up their own responsibilities and to express their problems more adequately.

Appendix
The Groningen Arousability Scale (GAS)

The intended subscale is shown between brackets.

When you become sexually aroused, does this give:

1. A pleasant "tingling" or "tickling" feeling in the genitals? (GSSUM)	0 very often 0 often 0 seldom 0 never
2. A "warm" feeling in the genitals? (GSSUM)	0 very often 0 often 0 seldom 0 never
3. A "pulsing" or "throbbing" feeling in the genitals? (GSSUM)	0 very often 0 often 0 seldom 0 never
4. A feeling of "pressure" or "fullness" in the genitals? (GSSUM)	0 very often 0 often 0 seldom 0 never
5. A feeling of tightening of the muscles in the pelvic area? (GSSUM)	0 very often 0 often 0 seldom 0 never
6. The feeling that the genitals are swollen? (GSSUM)	0 very often 0 often 0 seldom 0 never
7. Wetness or moisture in the genital area? (GSSUM)	0 very often 0 often 0 seldom 0 never
8. A feeling of tightening of the muscles of the womb? (GSSUM)	0 very often 0 often 0 seldom 0 never

9. A "numb" feeling? **(GSSUM)**
   0 very often
   0 often
   0 seldom
   0 never

When you have an orgasm, does this give:

10. A "relaxing" feeling? **(OSSUM)**
    0 very often
    0 often
    0 seldom
    0 never

11. A "pleasant" feeling? **(OSSUM)**
    0 very often
    0 often
    0 seldom
    0 never

12. A feeling of "pain"? **(NEGSENS)**
    0 very often
    0 often
    0 seldom
    0 never

13. A feeling of "release"? **(OSSUM)**
    0 very often
    0 often
    0 seldom
    0 never

14. An "emotional" feeling? **(OSSUM)**
    0 very often
    0 often
    0 seldom
    0 never

15. Can you become sexually aroused? **(CAPSUM)**
    0 very easily
    0 easily
    0 with some difficulty
    0 no

16. Are you able to have an orgasm? **(CAPSUM)**
    0 very easily
    0 easily
    0 with some difficulty
    0 no

17. Can you become sexually aroused by phantasising or thinking about arousing things? **(CAPSUM)**
    0 very easily
    0 easily
    0 with some difficulty
    0 no

18. Can you become sexually aroused by being touched on your genitals, by your partner, or yourself? **(CAPSUM)**

0 very easily
0 easily
0 with some difficulty
0 no

Does it ever happen that:

19. Your vagina feels "too narrow"? **(NEGSENS)**

0 very often
0 often
0 seldom
0 never

20. Your vagina feels "too short"? **(NEGSENS)**

0 very often
0 often
0 seldom
0 never

21. Your vagina feels "numb"? **(NEGSENS)**

0 very often
0 often
0 seldom
0 never

22. You have more than one orgasm within a short time? **(CAPSUM)**

0 very often
0 often
0 seldom
0 never

23. You take the initiative for making love? **(CAPSUM)**

0 very often
0 often
0 seldom
0 never

The Groningen Body-Image Scale

How important do you find the following body aspects with regard to yourself?
(please circle your choice)

		very unimportant	unimportant	important	very important
1.	face	1	2	3	4
2.	breasts	1	2	3	4
3.	waist	1	2	3	4
4.	hips	1	2	3	4
5.	buttocks	1	2	3	4
6.	external genitals	1	2	3	4
7.	internal genitals	1	2	3	4
8.	thighs	1	2	3	4
9.	figure	1	2	3	4
10.	style of behaviour	1	2	3	4
11.	general appearance	1	2	3	4
12.	voice	1	2	3	4
13.	hair	1	2	3	4
14.	body odour	1	2	3	4

How attractive do you find the following body aspects with regard to yourself?
(please circle your choice)

		very unattracktive	unattracktive	attracktive	very attracktive
1.	face	1	2	3	4
2.	breasts	1	2	3	4
3.	waist	1	2	3	4
4.	hips	1	2	3	4
5.	buttocks	1	2	3	4
6.	external genitals	1	2	3	4
7.	thighs	1	2	3	4
8.	figure	1	2	3	4
9.	style of behaviour	1	2	3	4
10.	general appearance	1	2	3	4
11.	voice	1	2	3	4
12.	hair	1	2	3	4
13.	body odour	1	2	3	4

The Groningen Arousability Scale: shortened female version (GAS-F)

When you become sexually aroused, does this give:

1. A pleasant "tingling" or "tickling" feeling in the genitals?
   0 very often
   0 often
   0 seldom
   0 never

2. A "warm" feeling in the genitals?
   0 very often
   0 often
   0 seldom
   0 never

3. A "pulsing" or "throbbing" feeling in the genitals?
   0 very often
   0 often
   0 seldom
   0 never

4. The feeling that the genitals are swollen?
   0 very often
   0 often
   0 seldom
   0 never

5. Wetness or moisture in the genital area?
   0 very often
   0 often
   0 seldom
   0 never

When you have an orgasm, does this give:

6. A "relaxing" feeling?
   0 very often
   0 often
   0 seldom
   0 never

7. A "pleasant" feeling?
   0 very often
   0 often
   0 seldom
   0 never

8. A feeling of "release"?
   0 very often
   0 often
   0 seldom
   0 never

9. An "emotional" feeling?
   0 very often
   0 often
   0 seldom
   0 never

10. Can you become sexually aroused?

0 very easily
0 easily
0 with some difficulty
0 no

11. Are you able to have an orgasm?

0 very easily
0 easily
0 with some difficulty
0 no

12. Can you become sexually aroused by phantasising or thinking about arousing things?

0 very easily
0 easily
0 with some difficulty
0 no

13. Can you become sexually aroused by being touched on your genitals, by your partner, or yourself?

0 very easily
0 easily
0 with some difficulty
0 no

14. Can you have more than one orgasm within a short time?

0 very often
0 often
0 seldom
0 never

CURRICULUM VITAE W.C.M. WEIJMAR SCHULTZ

Willibrordus Canisius Maria Weijmar Schultz was born in Rijssen on 30 Januari 1948. He attended primary school in Rijssen en Dieren and secondary school (HBSb) in Arnhem (Thomas a Kempis College). He completed his medical studies in 1973 at the Nijmegen University after a 4-months-internship in Tanzania. In preparation to his work in Africa postgraduate studies in surgery and gynaecology were completed in Nijmegen and Dordrecht.
From 1975-1977 he worked as a medical officer in the Akahaba Abiriba Joint Hospital, Abiriba, Nigeria. It was in Nigeria that he got married to Henryette Martine Van der Linden and received overthere a message from the Groningen University that he could specialize in Obstetrics and Gynaecology. A waiting period before starting his specialization was tide over by practizing in a nursing home in Gorinchem. After completing his specialization in 1983 he started the cooperation with Harry van de Wiel that culminated in this dissertation. The cooperation with Henryette culminated in the birth of his two "golden coins", Céline and Léon. His motto: there is a limit!

CURRICULUM VITAE H.B.M. VAN DE WIEL

Henricus Balthazar Maria van de Wiel was born in 's-Hertogenbosch on 26 June 1955. He attended primary school in 's Hertogenbosch and secondary school in 's Hertogenbosch (Stedelijk Gymnasium) and St. Michielsgestel (Gymnasium Beekvliet), which he completed after a thorough preparation of 8 years. From 1976 he worked in the daytime as a researcher at the "Nederlandse Stichting voor Psychotechniek" in Utrecht, while following evening courses in (clinical) psychology. He completed his study in 1982 at the Utrecht University, just after his wife Inez gave birth to their first daughter Floortje. From 1983 onwards he started the cooperation with Willibrord Weijmar Schultz, which is after all one of the best mistakes he ever made. During this period also his second daughter Anne and his son Pim were born. His motto: You can't make it alone.